Universität Basel
Fakultät für Psychologie

Comprehensive cancer care: Cancer patients' and oncologists' perspectives on psycho-oncological support

Inauguraldissertation zur Erlangung der Würde einer Doktorin der Philosophie vorgelegt der Fakultät für Psychologie der Universität Basel von

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Basel, 2018

Universität Basel

Fakultät für Psychologie

Genehmigt von der Fakultät für Psychologie auf Antrag von

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Datum des Doktoratsexamen: 18.01.2019

Dekan der Fakultät für Psychologie

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Manuskript 1:
Tondorf, T., Grossert, A., Rothschild, S.I., Koller, M.T., Rochlitz, C., Kiss, A., Schaefert, R., Meinlschmidt, G., Hunziker, S., & Zwahlen, D. Focusing on cancer patients' intentions to use psychooncological support: A longitudinal, mixed-methods study. *Psycho-Oncology*. 2018; 27:1656–1663. https://doi.org/10.1002/pon.4735

Manuskript 2:
Tondorf, T.*, Frey Nascimento, A.*, Rothschild, S.I., Koller, M.T., Rochlitz, C., Kiss, A., Schaefert, R., Meinlschmidt, G., Hunziker, S., Gaab, J., & Zwahlen, D. Oncologist Recommendation Matters! - Predictors of Psycho-Oncological Service Uptake in Oncology Outpatients. *Psycho-Oncology*. 2018. https://doi.org/10.1002/pon.4948 [Epub ahead of print]
*shared first authorship

Manuskript 3:
Tondorf, T., Rothschild, S.I., Koller, M.T., Rochlitz, C., Kiss, A., Grossman, P., & Zwahlen, D. Talking about psychosocial distress screening: what oncologists and cancer patients recall. (under review in *Supportive Care in Cancer*)

Theresa Tondorf Basel, Januar 2019

„Der Mensch aber lebt nur ein Leben, er hat keine Möglichkeit, die Richtigkeit der Hypothese in einem Versuch zu beweisen. Deshalb wird er nie erfahren, ob es richtig oder falsch war, seinem Gefühl gehorcht zu haben.“

(Milan Kundera, 1984)[1]

[1] Milan Kundera (1984). *Die unerträgliche Leichtigkeit des Seins*. Fischer Taschenbuch Verlag, Frankfurt am Main, p. 36.

Contents

Acknowledgments

My greatest thanks to the people who participated in the study and were willing to share their deepest thoughts and feelings to help improve comprehensive cancer care in the future. Catching a glimpse of their individual circumstances made it possible to consolidate the findings at a more profound level. The insights gained did not only contribute to my knowledge as a researcher but also to my professional development as a clinical psychologist and to my personal growth as a human being.

Project funding from Krebsliga Schweiz and personal funding from Freiwillige Akademische Gesellschaft Basel made it possible for me to work on this project for five years. I was accompanied by Diana Zwahlen, whose untiring energy, constant effort, and ongoing confidence endured through turbulent times. Additionally, I was fortunate to work with seven excellent master students, who were highly motivated and dedicated to the project: Sandra Basset, Antje Frey Nascimento, Silke Hogg, Luzia Inauen, Jael Mattmann, Milena Petignat, and Annik Schaad. I was privileged to conduct this research as a member of a highly committed interdisciplinary team at the department of medical oncology at the University Hospital Basel, striving for the best bio-psycho-social cancer care. My special thanks goes to the oncology team, notably to Christoph Rochlitz, Sacha Rothschild, and to all the oncologists who made a valuable contribution to this study beyond their daily work. Thanks also to the team at the Department of Psychosomatic Medicine, notably Alexander Kiss, Astrid Grossert, and all the psycho-oncologists, for being a psychological home base. Additionally, I wish to thank Michael Koller for his significant statistical backing and mutual thought processes and Claudia Steiner for her linguistic amendments. I am very grateful to Jens Gaab for his faith in me and for his outright and effective support at critical moments. Whenever I felt stuck, he provided an open ear and mind, suggesting solutions, and encouraging me to go on.

My deepest thanks to Marlies, Jürgen, and Anne for their imperturbable love and support. Without them, it would not have been possible for me to find my own way, settle down, and feel strong enough to succeed. I also thank my dearest friends for sharing, discussing, and laughing, notably Helena Hermann for coming along on this journey. Looking back onto these last years, I end a long walk, accompanied by many people, full of good memories, and enriched with valuable experiences. I dedicate this thesis to the feeling of pleasure and effort, to endlessness, the burning sensation, and silliness.

Abstract

Background. Cancer is a potentially life-threatening disease with increasing survival rates attended by adverse effects on physical and psychological well-being. In routine oncology practice, psychological complaints are often neglected, and many patients who might benefit from psychosocial support do not receive these services. To understand patients' psychosocial health care needs and towards evidence-based change in clinical practice, patients' needs are approached from the differing perspectives of the patient and the oncologist. **Methods.** We conducted a prospective, observational single-centre study in the Oncology Outpatient Clinic at the University Hospital Basel (Switzerland). Using the Distress Thermometer (DT), patients were routinely screened for psychosocial distress before their first consultation. Oncologists (n=25) then discussed distress and support options with patients (n=333). After the consultation, the oncologist's perception of the conversation and screening procedure was assessed by means of a questionnaire. The patient's perception of the conversation, as well as their psychosocial distress, support needs, and uptake of psycho-oncological service, were captured in two semi-structured interviews and questionnaires over a period of four months and analyzed using a mixed-methods approach. **Results.** The analysis revealed that more than half of all cancer patients experienced elevated levels of psychosocial distress (DT≥5). Two-thirds of all cancer patients were clear about their intention (*yes or no*) to use the psycho-oncology service while one third remained ambivalent (*maybe*). Patient intention was determined by perceived distress, attitude to psychological support, and coping strategies, as well as by other social and professional support. After four months, 23% of all patients had attended the psycho-oncology service (65% with *yes intention*, 12% with *maybe intention*, 7% with *no intention*). Patients who perceived a recommendation from their oncologist or who were not sure if they had perceived a recommendation were more likely to attend the

psycho-oncology service than those who clearly did not perceive a recommendation from their oncologist, as were younger patients, highly educated patients, and patients with high distress scores. In almost all cases, oncologists used this distress screening to open the conversation about psychosocial issues in the first consultation. However, patients often failed to recall this conversation, and this failure was predicted by higher age, higher distress, and attaching less importance to talk with the oncologist about distress. **Conclusion.** Severity of distress is associated with patient need for psycho-oncological support but is not the only deciding factor. Many patients are ambivalent about psycho-oncological support and rely on oncologists to recommend these services. Repeated distress screenings, detailed information about the psycho-oncology service during the cancer trajectory, and an explicit recommendation from the treating oncologist to attend psycho-oncological services may improve comprehensive cancer care and prevent adverse effects on long-term psychological well-being among vulnerable cancer patients.

1 Preface

Medical instruments measure CRP, PSA, and body temperature; machines analyse BRCA1/2, HER-2, and ER; PET-CTs, X-Rays, and mammography scans capture images of body cells. After undergoing all these tests and procedures, as well as pain and uncertainty, oncologists tell their patients that they have cancer—a malignant tumour involving degenerated cells that proliferate uncontrollably. This news causes shock and speechlessness in almost all patients. Standard procedures are then explained, treatment plans are outlined, and the next steps are discussed. At that moment, the most important thing for many patients are the restoration of support, control, and hope in a potentially life-threatening situation. During the medical treatment, which may involve chemotherapy, surgery, radiotherapy, immunotherapy, and so on, clinicians attend to all kinds of physical side effects like pain, nausea, diarrhoea, mucositis, and dermatitis, which strongly affect patients' psychological well-being. However, in many cases, there is less attention to psychological side effects like disappointment, anger, fear, grief, sadness, hopelessness, identity crisis, altered body perception, and sorrow about one's family and about the future. Although ubiquitous in everyday life, these psychological complaints may not be voiced, as survival is the principal goal. Yet as survival rates among cancer patients increase, psychological aftereffects like vulnerability, existential angst, depression, and fear of recurrence may be disabling, persisting for years or decades unless heard and addressed.

Today, short psychosocial distress screenings are implemented in routine clinical oncology practice to identify cancer patients with psychological side effects and to initiate referral to psycho-oncological services. However, many cancer patients with high levels of psychosocial distress who might benefit from psycho-oncological support do not attend these services. Factors other than psychosocial distress might influence psychosocial

health care needs of cancer patients (e.g. patient-, organization-, communication-related factors). To improve comprehensive cancer care for cancer patients in need of supportive care services, the aim of the present study was to listen to the psychosocial health care needs of cancer patients and to patients' and oncologists' perspectives by understanding a) patients' intentions to use psycho-oncological support, b) predictors of psycho-oncological service uptake, and c) patients' and oncologists' perceptions of the conversation about psychosocial issues and psycho-oncological support.

In a cumulative approach, the thesis draws on three publications accepted by or submitted to peer-reviewed scientific journals. These are embedded in an introductory section illustrating the two perspectives and inform the subsequent discussion of key findings. The insights gained are of relevance to international research in psycho-oncology and to everyday practice in clinical oncology. Most importantly, the research will benefit cancer patients by helping to reduce their suffering through listening, learning, and reinforcing their voice.

2 Introduction

2.0 Background

2.0.1 Cancer as major health concern

Cancer is a major health concern worldwide. Advances in early diagnostics and more effective treatments mean that an increasing number of people affected by cancer will survive (Mehnert & Hartung, 2015). There are currently more than 15.5 million cancer survivors in the USA (Miller et al., 2016); in Switzerland there will be 372,000 cancer survivors by the end of 2020 (as compared to 289,797 in 2010; Herrmann et al., 2013). In short, mortality rates among patients diagnosed with cancer are decreasing, with longer progression-free survival rates for patients with non-curable cancers (Herrmann et al., 2013). However, this means that the long-term side effects of cancer treatments are also prolonged. For many, cancer becomes a chronic disease; for others, it remains a life-threatening disease. As both situations are attended by adverse short- and long-term effects on physical and psychological well-being (Mehnert & Hartung, 2015), health care policies in many countries now prioritise comprehensive care for cancer patients (Institut of Medicine, 2008; National Comprehensive Cancer Network, 2014; Schweizerische Gesellschaft für Psychoonkologie, 2014).

2.0.2 Barriers to comprehensive cancer care

In 2008, an influential report from the Institute of Medicine concluded that although there was evidence of the effectiveness of psychosocial support, many cancer patients who might benefit from psychosocial care did not attend these services (Institut of Medicine, 2008). In 2014, a nationwide study involving 21,151 cancer patients in the UK demonstrated that 73% of cancer patients with comorbid major depression were still not

receiving any treatment for their depression (Walker et al., 2014). Of the remainder, 24% were prescribed antidepressants, and only 5% were seeing a mental health professional (Walker et al., 2014). The reasons for this lack of adequate psychosocial support include failure to detect mental disorders in the oncology setting; failure to provide psychosocial services at all settings (e.g. inpatient and outpatient settings); a lack of information about available services; no mandatory communication skills trainings for physicians; restricted consultation time; and sparse financial resources. Additionally, as there is (still) a stigma attached to mental illness and psychological support, patients may refuse support.

Psychosocial distress screening (e.g. the Distress Thermometer (DT), see Appendix B) was implemented in routine clinical practice to improve comprehensive cancer care. The goal was to enable clinicians to rapidly identify cancer patients with elevated psychosocial distress and to initiate referral to psychosocial services (Carlson, Waller, & Mitchell, 2012; Fann, Ell, & Sharpe, 2012; Holland, Watson, & Dunn, 2011; Jacobsen, Holland, & Steensma, 2012). Today, distress screening programmes are mandatory in many countries for institutional certification as a Comprehensive Cancer Centre, as specified in guidelines, and international standards for comprehensive care of cancer patients (Bultz et al., 2015; Donovan, Grassi, McGinty, & Jacobsen, 2014; Lazenby et al., 2015; National Comprehensive Cancer Network, 2014; Pirl et al., 2014; Zebrack et al., 2015). However, as observed by Jimmie Holland, one of the founders of the field of psycho-oncology, ‘it is clear that establishing guidelines alone is not sufficient to change care’ (p. 677; Holland et al., 2011).

2.0.3 Two perspectives: patient and oncologist

To remove the barriers to accessing appropriate supportive care services for cancer patients in need of psycho-oncological support, and to achieve meaningful and sustained changes in clinical practice, three perspectives on evidence-based medicine must be considered: the *patient's perspective* (i.e. patient values & expectations), the *oncologist's perspective* (i.e. clinical expertise), and the *empirical evidence perspective* (i.e. best external evidence; Figure 1; Kent et al., 2015; Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996).

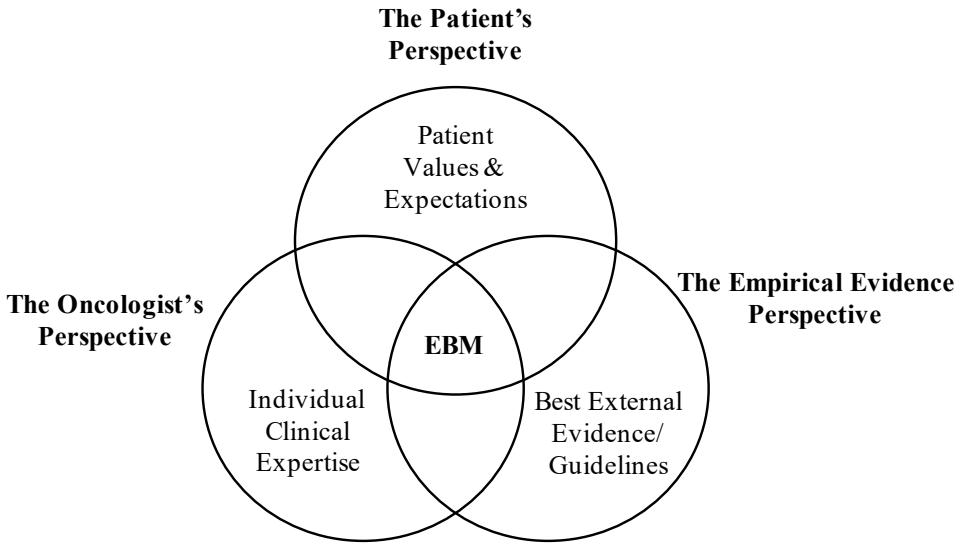

Figure 1. Evidence-based medicine (EBM) triad (adapted from Armstrong, 2003).

To date, the narratives of oncologists and patients have been largely overruled by more rigorous scientific evidence (e.g. randomized controlled trials; Kiss, 2015; Meisel & Karlawish, 2011). However, empirical evidence is useless if it cannot be applied in everyday clinical practice, and for that reason, the perspective of patients and oncologists are crucial (Kiss, 2015). In the present study, the aim was to revisit these two perspectives in the context of the current empirical evidence.

2.1 The patient's perspective

2.1.1 Psychosocial distress in patients with cancer

The diagnosis of cancer evokes a range of emotional reactions in patients and their relatives, such as fear, anger, and sadness. Reacting emotionally to a potentially life-threatening situation is normal, and all cancer patients experience some level of psychological distress during their disease trajectory from first indicators through diagnosis, effects, and treatment and on to the palliative or survivorship phase. According to the NCCN Guidelines (National Comprehensive Cancer Network, 2014):

Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can be disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. (p. DIS-2)

One cancer patient in every two suffers from subsyndromal levels of psychosocial distress (Carlson et al., 2004; Carlson, Groff, Maciejewski, & Bultz, 2010; Mitchell et al., 2011; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). Cancer patients with untreated high levels of psychosocial distress are at risk for comorbid mental disorders (Mehnert et al., 2014; Mitchell et al., 2011; Singer, Das-Munshi, & Brähler, 2010).

2.1.2 Prevalence of mental disorders in cancer patients

Mehnert and colleagues reported a 4-week prevalence rate of 31.8% for any mental disorder in a large German population of cancer patients (Mehnert et al., 2014), which is high when compared to the rate for the general population (20%; Jacobi et al., 2004). The

most common comorbid mental disorders include anxiety disorders (11.5%), adjustment disorders (11.0%), and mood disorders (6.5%; Mehnert et al., 2014). Additionally, many cancer-specific emotional states such as fear of cancer recurrence, demoralization, and subsyndromal psychosocial distress are not recorded in prevalence studies (Herschbach, 2015). Psychological symptoms in cancer patients often fluctuate, they are closely linked to physical state and medical findings, and can be difficult to diagnose because of overlapping psychological and somatic symptoms (e.g. insomnia, fatigue, low appetite; Mitchell, Lord, & Symonds, 2012). Left untreated, psychiatric comorbidity can have significant adverse consequences for cancer treatment and survival, as these patients are at risk for non-adherence to cancer treatment (Kennard et al., 2004), reduced quality of life (Skarstein, Aass, Fossa, Skovlund, & Dahl, 2000), increased suicide risk (Kissane, 2014), and a four times higher rate of requests for euthanasia (Van Der Lee et al., 2005).

2.1.3 Evidence for psycho-oncological intervention

Evidence from studies and meta-analyses confirms that psycho-oncological interventions such as individual or group psychotherapy, psychoeducation, and relaxation training significantly enhance quality of life, with a small-to-medium effect in reducing psychosocial distress, anxiety, and depression, and a medium-to-large effect when considering only those studies that preselected for highly distressed cancer patients (Faller et al., 2013; Gorin et al., 2012; Herschbach, 2015; Jacobsen et al., 2012; Kangas, Bovbjerg, & Montgomery, 2008). However, there is also evidence that psychological support is not beneficial for all cancer patients (Zhu et al., 2015), that many distressed cancer patients do not attend psycho-oncological support (Brebach, Sharpe, Costa, Rhodes, & Butow, 2016), and that 37–54% of cancer patients report unmet supportive care needs (Beesley, Janda, et al., 2016; Faller, Koch, et al., 2016; Mehnert & Koch, 2008; Sanson-Fisher et

al., 2000). On that basis, there is a need for more studies of specific psycho-oncological interventions for different groups of cancer patients (e.g. young vs. old; women vs. men).

2.1.4 Supportive care needs of patients with cancer

Although some studies have shown that prevalence of high distress (*normative need*) and desire for support (*felt need*) are statistically correlated (Admiraal, van Nuenen, Burgerhof, Reyners, & Hoekstra-Weebers, 2016; van Scheppingen et al., 2011), other studies show no such correlation (Merckaert et al., 2010; Söllner, Maislinger, König, Devries, & Lukas, 2004). In fact, among cancer patients with high levels of psychosocial distress, 42–75% fail to report a need for psycho-oncological support (Baker-Glenn, Park, Granger, Symonds, & Mitchell, 2011; Carlson et al., 2004; Clover, Mitchell, Britton, & Carter, 2014; Shimizu et al., 2010; Söllner, Maislinger, König, Devries, & Lukas, 2004; van Scheppingen et al., 2011) while 10–44% of patients with low levels of psychosocial distress report a need for support (Bonacchi et al., 2010; Faller, Weis, et al., 2016; Söllner et al., 2004; van Scheppingen et al., 2011).

Factors that predict need for supportive care include younger age, female sex, higher education, advanced cancer, shorter time since diagnosis, and greater symptom burden (Faller, Weis, et al., 2016; Fiszer, Dolbeault, Sultan, & Brédart, 2014). However, referring patients with a high level of distress to supportive care services has proved very difficult. Salmon and colleagues (Salmon, Clark, McGrath, & Fisher, 2015) explain this discrepancy from a health care perspective, concluding that need for supportive care entails three aspects: an expert-defined *normative need* for support (e.g. an elevated distress score on a screening tool) and a patient's *felt need* (i.e. a wish or desire) for

support, which may become an *expressed need* for support (i.e. clear statement of intent to use a service) provided there is a known and available support service (see Figure 2).

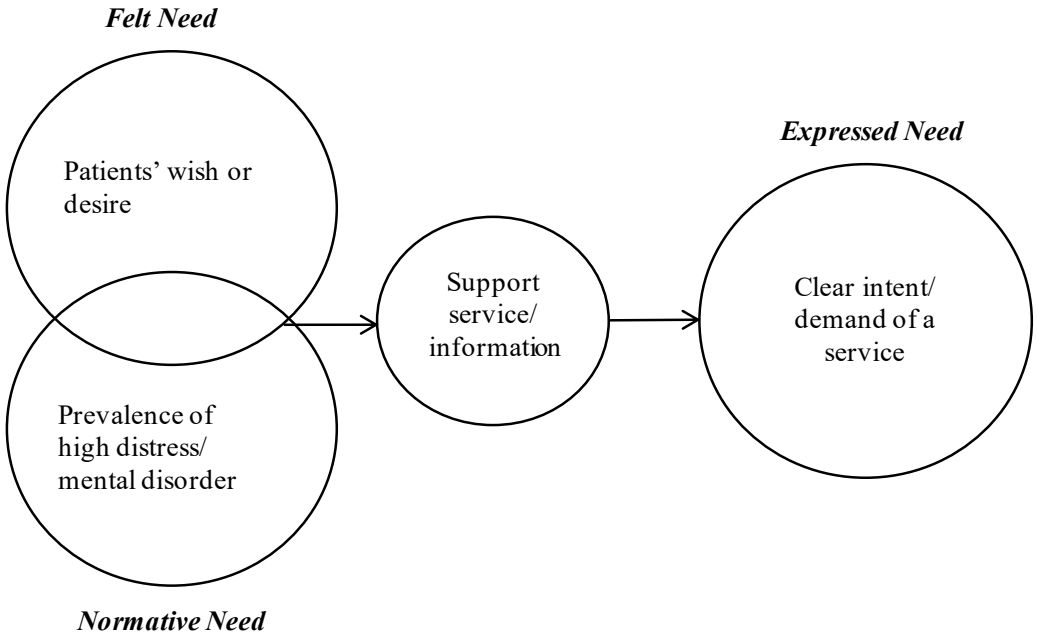

Figure 2. Need for psychological support from a health care perspective (adapted from ideas of Bradshaw et al., 2013, Salmon et al., 2015, and Sartorius, 2012).

Patient need is an important indicator of whether professional help is wanted, but only a few qualitative studies have assessed patients' reasons for declining psycho-oncological help despite reporting high distress levels (Clover et al., 2015; Mosher et al., 2014). Using eight pre-selected answers, Clover and colleagues found that highly distressed patients did not want psycho-oncological support principally because they preferred to manage themselves, they received help from another source, or they did not feel sufficiently distressed (Clover et al., 2015).

2.1.5 The gap between support need and uptake

Not every *felt need* becomes an action (*expressed need*; Bradshaw, Cookson, Sainsbury, & Glendinning, 2013). One meta-analytic study found that uptake of psychological support in a clinical setting was 50%; once enrolled, however, 90% adhered to the support service (Brebach et al., 2016). A number of studies have examined barriers to uptake of psychosocial care, such as not knowing where to get help, a belief that the treatment does not work, concerns about what other people might think, and additional cost or effort (Dilworth, Higgins, Parker, Kelly, & Turner, 2014; Mosher et al., 2014; Neumann et al., 2010). Most of these barriers could be addressed at informational and organizational level by offering adequate and low-threshold support services, informing patients about how a psychologist can help, and including psychosocial care in routine cancer care to reduce stigmatization (Azuero, Allen, Kvale, Azuero, & Parmelee, 2014). The fact that highly distressed patients who most likely benefit from psychological support do not engage with psychosocial support services invites formulation of more suitable offerings by listening to what cancer patients actually need.

2.2 The oncologist's perspective

2.2.1 Let's talk about psychosocial distress

Psychosocial distress in cancer patients often goes unrecognized in routine oncology practice (Detmar, Aaronson, Wever, Muller, & Schornagel, 2000; Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Söllner et al., 2001). Although physicians have become increasingly aware of their responsibility to address cancer patients' psychosocial issues, they still hesitate or rely on patients to initiate this discussion (Absolom et al., 2011; Taylor et al., 2011). One UK study showed that 59% of cancer patients and 75% of physicians said they would initiate a discussion about psychological issues; a further 30% of patients

said they would wait for the physician to address this issue. However, audio-recordings showed that psychological concerns were discussed in only 27% of all consultations and were mainly introduced by patients (85%; Taylor et al., 2011).

Among oncologists, barriers to psychosocial communication with cancer patients include lack of consultation time, lack of support and feedback from colleagues and leaders, lack of resources to address upcoming problems, lack of methods and routines to evaluate distress, and skills deficits in communicating about psychosocial issues (Fagerlind, Kettis, Glimelius, & Ring, 2013). In general, physicians still seem to fear opening a Pandora's box that cannot be closed, but the available evidence suggests otherwise; in fact, addressing psychological issues does not prolong consultation time (Eijzenga et al., 2014; Velikova et al., 2004), and most cancer patients appreciate the opportunity to discuss psychological concerns, which validates their needs (Jones, Regan, Ristevski, & Breen, 2011; Mackenzie, Carey, Sanson-Fisher, D'Este, & Yoong, 2015) without expecting oncologists to respond to their problem as psychologists might (Wright, Holcombe, & Salmon, 2004).

2.2.2 Unsuccessful patient-oncologist communication

Patient-oncologist communication is particularly challenging because of the intensity of emotions, the complexity of treatment options, and uncertainty about the future (Epstein & Street, 2007). Many studies have shown that patients' and clinicians' perceptions of what has been discussed consistently varies (Epstein, Prigerson, OReilly, & Maciejewski, 2016; L. J. Fallowfield et al., 2017; Jenkins et al., 2011). While 58% of patients reported that fatigue limited their daily life more than pain while undergoing cancer treatment, only 29% of oncologists shared this perception (Williams, Bohac, Hunter, & Cella, 2016). Gabrijel and colleagues (Gabrijel et al., 2008) found that 51% of lung cancer patients failed to recall information about the treatment goal (i.e. whether the primary intent of the

treatment was to cure the cancer) even though physicians reported having shared this information. Reasons for such mismatches of understanding can be identified on both sides; either physicians fail to fully or unambiguously disclose essential information, or patients fail to retain that information or are overly optimistic about their future.

In addition, it is well known that patients remember only about seven items of information per consultation, provided that the physician uses a simple language, structures the conversation, delivers information in small units, and supplies the patient with additional written information (Finset, 2015; Kessels, 2003; Langewitz et al., 2015).

2.2.3 Successful patient-physician communication

In situations of existential threat, people look for a clinical relationship with someone they can trust, who is experienced, and who will guide them through the next steps (Beesley, Goodfellow, Holcombe, & Salmon, 2016). Physicians, on the other hand, seek to improve their patients' situation by gathering as much information as possible and understanding the patient's needs while performing a balancing act between telling the truth and sustaining hope (Bousquet et al., 2015; Langewitz, 2009).

To achieve their respective goals, patients and physicians must be able to communicate successfully. Although this is a difficult task, effective communication has the potential to reduce cancer patients' depression and anxiety (Fujimori et al., 2014; Schofield et al., 2003), increase adherence to cancer treatments (Grassi et al., 2017), improve satisfaction with care (Merckaert et al., 2015), and encourage patients to accept additional support (Jones et al., 2011). Oncologists whose training is psychosocially oriented see fewer barriers to communication (Fagerlind et al., 2013) and more frequently initiate communication about psychosocial distress (Book et al., 2013). It can be concluded that physicians can and should be educated in communication skills.

2.2.4 Communication skills training

To improve communication during cancer care, communication skills training (CST) has been mandatory for oncologists in Switzerland since 2001 (Stiefel et al., 2011). Many studies have shown CST's consistent effect on physicians' communication skills and satisfaction (Barth & Lannen, 2011) but not on patient outcomes (Langewitz, 2017). One criticism is that CST focuses mainly on communication skills (e.g. maintaining eye contact, structuring information) rather than addressing the communication context as a whole (Stiefel & Bourquin, 2016), although we know that communication always happens in a context built by two (or more) persons who move in relation to each other like the swinging parts of a mobile (Langewitz, 2009).

In several studies of surgeons and women with breast cancer, Salmon and colleagues found that patients' trust in the clinical relationship was built on the clinician's expertise and authority rather than through emotional engagement (Beesley et al., 2016; Salmon, Mendick, & Young, 2011; Wright et al., 2004; Young et al., 2013). In general, it is considered more helpful when, without disregarding the patient, physicians avoid displaying too much empathy. In the interest of their own health as well as the patient's, oncologists need the professional skill to oscillate between proximity and distance, and between empathy and facts (Kiss, 2016). Oncologists bear a significant emotional burden and are at risk of exhaustion and burnout, which relate significantly to time spent with patients (Eelen et al., 2014).

3 Methods

3.1 Research project

3.1.1 Objectives

The research project entitled "Understanding why cancer patients accept or turn down psycho-oncological support. A prospective observational study including patients' and clinicians' perspectives on communication about distress" emerged from a practical concern about clinical relevance. The objectives of the project were to assess barriers and predictors for uptake of psycho-oncological support in cancer patients and to determine how patients and oncologists perceive the conversation about psychosocial distress following screening. The study addressed the following research questions.

1. From the patient's perspective, what proportion of cancer patients intend, maybe intend, or do not intend to use the psycho-oncology service? Why do patients intend, maybe intend, or do not intend to use the psycho-oncology service? Which patient-related and patient-oncologist communication-related variables predict uptake of psycho-oncology services?
2. From the oncologist's perspective, how do oncologists make use of psychosocial distress screening procedures? Is there a difference between patients' and oncologists' recall of the conversation about psychosocial distress and psycho-oncological support?

We conducted a prospective, observational single-centre study in the Oncology Outpatient Clinic at the University Hospital Basel (Switzerland). The study was approved by the local ethics committee (Ethikkommission Nordwest- und Zentralschweiz, Ref.Nr. EK 220/13) and was funded by Krebsliga Schweiz. The methods used are summarised here; a detailed description is included in the study protocol (Zwahlen et al., 2017; see Appendix A).

3.1.2 Participants

The study participants were cancer patients who presented for the first time at the Medical Oncology Outpatient Clinic at the University Hospital Basel between October 2013 and January 2016. To be included, patients had to be diagnosed with any solid tumour or hematologic malignancy, older than 18 years, fluent in German, physically and cognitively well enough to participate, and scheduled for at least one further consultation. Patients were pre-screened by their attending oncologist for eligibility and interest in joining the study. The participating clinicians were oncologists and residents from the hospital's Medical Oncology Department.

3.1.3 Standard distress screening procedure

Based on a stepped–care model (National Comprehensive Cancer Network, 2014), all cancer patients were routinely screened for psychosocial distress at their first outpatient consultation. Before their first consultation with the oncologist patients completed the DT in the waiting room; the form included a description of the outpatient psycho-oncology service (see Appendix B). Where possible, the oncologist discussed the DT with the patient during the first consultation. Oncologists were advised to provide information about the psycho-oncology service to all patients and to recommend the service to those displaying a clinically relevant level of distress (DT≥5), or based on their clinical judgment or the patient's wishes. The oncologists were trained in communication about psychosocial distress and referral to the psycho-oncology service. The psycho-oncological team was situated on the ward and integrated in the medical oncology team.

3.1.4 Study procedure

Following pre-screening by the attending oncologists, the study team informed eligible and interested patients about the study procedure. After signing the informed consent,

participants were interviewed by a member of the study team after the first consultation and again four months later. Participants received baseline and follow-up questionnaires by mail. Interviews were conducted by telephone or face-to-face, according to patient preference. Based on an interview manual, the interviews were semi-structured and conversational, and the interviewer made notes of the patient's answers to open-ended questions. The oncologists completed a paper-pencil questionnaire after each consultation with a new patient. Figure 3 details the study procedure and measures.

3.1.5 Measures

Data were collected at three points in time (t1 screening, t2 baseline, t3 follow-up), using paper-and-pencil questionnaires and two semi-structured interviews (for details see Figure 3 and Appendix A). Patients' reasons for (non-)uptake of the psycho-oncology service were recorded in the interviews and qualitatively analysed. The primary outcome (at least one appointment at the outpatient psycho-oncology service) was retrieved from patients' medical records four months after their entry to the study.

3.1.6 Data analysis

Quantitative data were analysed using SPSS version 22 (IBM, Armonk/NY, 2013). Descriptive methods were used to capture the frequency of categorical variables and the distribution of continuous variables. Contingency table analyses were used to assess agreement between patients' and oncologists' perceptions. Univariate and multivariate logistic regression analyses were used to assess the impact of predictor variables on uptake of the psycho-oncology service. Missing data were analysed, using multiple imputation where data were consistent with complete case analyses. Significance level was $p \leq .05$.

Answers to open-ended questions were edited using MAXQDA 12 (VERBI Software, Germany) software for qualitative analysis and analysed using content analysis

(Mayring, 2008). To ensure high quality content analysis, a team of trained researchers discussed the data. Inter-rater reliability was assessed using Cohen's kappa statistics (κ).

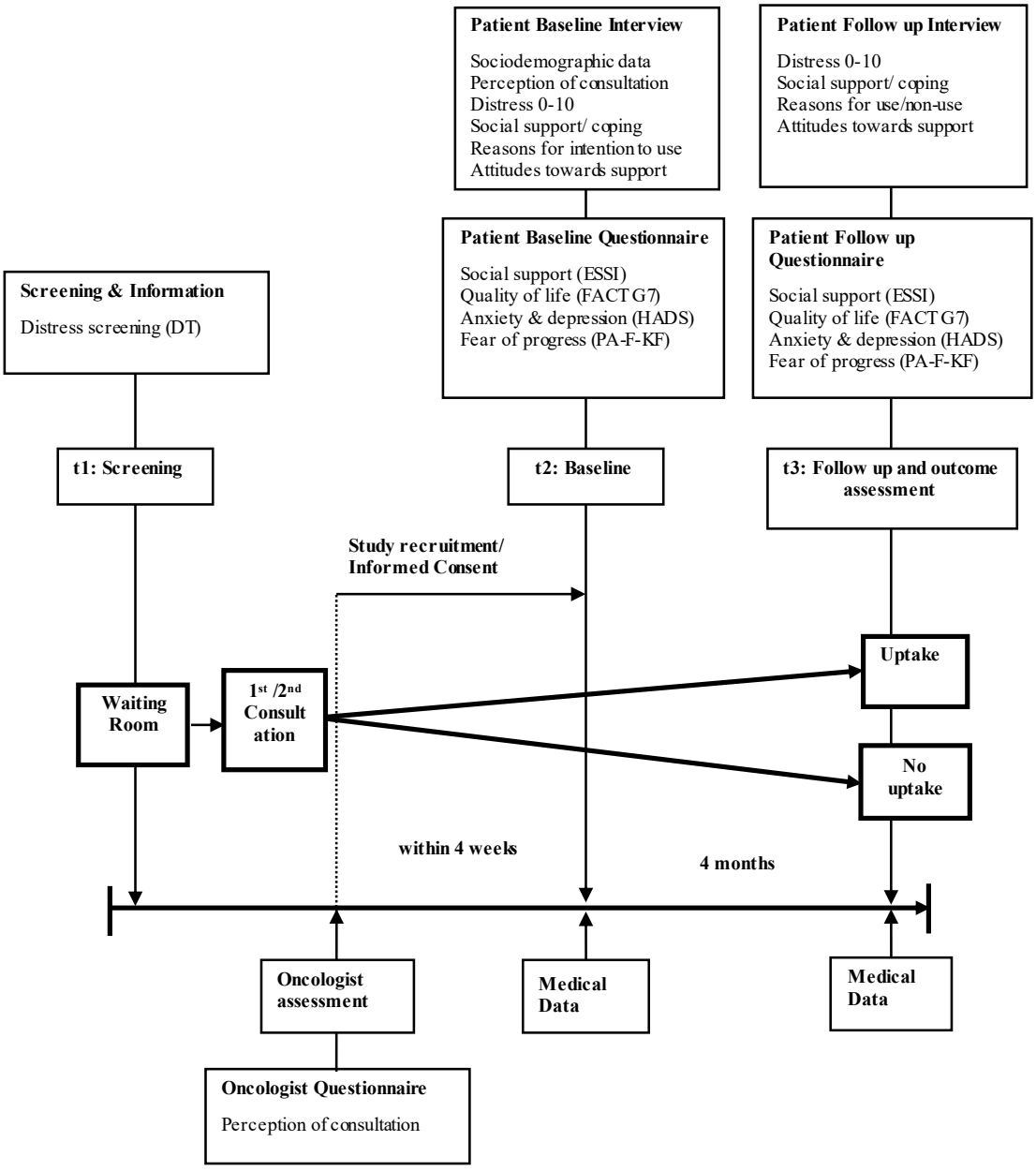

Figure 3. Study procedure and study measures.

4 Publications

4.1 Focusing on cancer patients' intentions to use psychooncological support: A longitudinal, mixed-methods study

Received: 23 October 2017 | Revised: 5 April 2018 | Accepted: 6 April 2018

DOI: 10.1002/pon.4735

PAPER

WILEY

Focusing on cancer patients' intentions to use psychooncological support: A longitudinal, mixed-methods study

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Funding information
Swiss Cancer League, Grant/Award Number: KLS-3186-02-2013

Abstract

Objective: Distress screening programs aim to ensure appropriate psychooncological support for cancer patients, but many eligible patients do not use these services. To improve distress management, we need to better understand patients' supportive care needs. In this paper, we report the first key finding from a longitudinal study that focused on patients' intentions to use psychooncological support and its association with distress and uptake of the psychooncology service.

Methods: We conducted a prospective, observational study in an Oncology Outpatient Clinic and assessed distress, intention to use psychooncological support, and uptake of the psychooncology service by using the Distress Thermometer, a semistructured interview, and hospital records. We analyzed data with a mixed-methods approach.

Results: Of 333 patients (mean age 61 years; 55% male; 54% Distress Thermometer ≥ 5), 25% intended to use the psychooncology service (yes), 33% were ambivalent (maybe), and 42% reported no intention (no). Overall, 23% had attended the psychooncology service 4 months later. Ambivalent patients reported higher distress than patients with no intention (odds ratio = 1.18, 95% confidence interval [1.06-1.32]) but showed significantly lower uptake behavior than patients with an intention (odds ratio = 14.04, 95% confidence interval [6.74-29.24]). Qualitative analyses revealed that ambivalent patients (maybe) emphasized fears and uncertainties, while patients with clear intentions (yes/no) emphasized knowledge, attitudes, and coping concepts.

Conclusions: We identified a vulnerable group of ambivalent patients with high distress levels and low uptake behavior. To optimize distress screening programs, we suggest addressing and discussing patients' supportive care needs in routine clinical practice.

KEYWORDS

cancer, Distress Thermometer, health-care delivery, needs, oncology, psychological support, psychooncology, reasons, screening, uptake

1 | BACKGROUND

Cancer patients with untreated, high levels of psychosocial distress are at risk for nonadherence to cancer treatment,[1] reduced quality of life,[2] and comorbid mental disorders.[3-6] Psychooncological interventions can effectively reduce distress,[7] but many eligible patients do not take advantage of support services.[8,9] A third of all cancer patients show clinically significant levels of psychosocial distress,[3] but more than half of them do not want psychooncological support (42-75%),[10-15] although many patients with less distress do want support (10-44%).[11,15-17] Even patients who want and are offered psychooncological support do not always use these services.[18] Guidelines highlight the need to understand patients' supportive care needs to remove barriers and facilitate access to psychosocial services.[8,18-20]

Salmon et al[20] referring to Jonathan Bradshaw[21] recently brought patients' supportive care needs into focus by acknowledging that there is not only a *normative need* for support (defined by experts), indicated by an elevated distress score on the Distress Thermometer (DT) or other screening instruments, but also a *felt need* for support like a wish or desire that can become an *expressed need* for support, indicated, for example, by an expression of clear intent to use the known and available psychooncology service. Previous studies examined why a cancer patient's distress level did not always conform to their wish for support or adherence to services.[10,17,18,22-25] Most studies have focused on patients with high distress levels, and few used qualitative methods to understand patients' needs.[26,27]

We took an inductive, qualitative approach to understanding patients' supportive care needs without dividing them a priori into low- and high-distress groups. Our longitudinal mixed-methods design supplemented qualitative analysis with quantitative assessment of distress and uptake of the outpatient psychooncology service in a longitudinal mixed-methods design. We formulated 3 research questions: (1) What proportion of cancer patients intends, maybe intends, and does not intend to use the psychooncology service? (2) How are patients' intentions associated with distress and uptake of service? (3) Why do patients intend, maybe intend, and not intend to use the psychooncology service?

2 | METHODS

We report findings from a prospective, observational study in the Oncology Outpatient Clinic of the University Hospital Basel (Switzerland). Our methods are briefly outlined below; we have described them in more detail elsewhere.[28]

2.1 | Participants

Cancer outpatients who presented for the first time and used the outpatient oncological care at the clinic were eligible when fulfilling the inclusion criteria: ≥18 years, fluent in German, not being physically or cognitively impaired in a way that impedes study participation, and having at least 1 further consultation planned with an oncologist.

2.2 | Standard screening and referral procedure

Based on a stepped-care model,[19] patients were routinely screened with the DT at their first outpatient consultation for psychosocial distress. A nurse asked patients to fill in the DT, which patients then handed to the oncologist. All patients were given written information about the outpatient psychooncology service. The service is available for free and on short notice for all outpatients. Oncologists were briefed to address psychosocial distress during the first consultation and to recommend the service to patients, based on a clinically relevant distress level (DT ≥ 5), their clinical judgment, or the patient's wish.

2.3 | Study procedure

Oncologists screened cancer patients for interest to participate. The study team informed interested patients about the study, obtained informed consent, and interviewed participants an average of 15 days after the first consultation. Semistructured interviews were conducted in German and over the phone or face-to-face. Interviewers (TT and 7 Master's level students) relied on a manual. They were trained to use comprehension questions, reflection, and summaries to clarify mutual understanding; to take notes on participants' answers to open-ended questions during the interview, verbatim if possible; and to make postscripts of the interviews immediately afterward.[29] This study complied with the Declaration of Helsinki. The local ethics committee approved the study (Ethikkommission Nordwest-und Zentralschweiz, ref. no.: EK220/13).

2.4 | Measures

2.4.1 | Sociodemographic and clinical characteristics

Patients' sociodemographic data were recorded during the interview. Clinical data were collected from patients' medical records.

2.4.2 | Psychosocial distress screening

We used the German version of the National Comprehensive Cancer Network DT to assess self-reported psychosocial distress on a visual analogue scale from 0 to 10.[30] The 1-item screening tool shows good reliability and validity and has a cutoff value of ≥5 for clinically significant levels of psychosocial distress (from 0 "no distress" to 10 "extreme distress").[30]

2.4.3 | Intention and reasons for uptake of psychooncological support

We asked the participants about their prospective intention during the interview: "Do you intend to uptake the outpatient psycho-oncological support service in the next months?" The interviewer categorized the participants' responses into 3 answers (yes/maybe/no), followed by an open-ended question: "What are the reasons why you do [may/not] intend to use the outpatient psycho-oncological support service?"

2.4.4 | Uptake of the outpatient psychooncology service

We defined uptake as having attended at least one appointment at the outpatient psychooncology service within 4 months after study entry and retrieved this information from hospital records.

2.5 | Data analyses

2.5.1 | Quantitative analyses

We conducted descriptive analyses for sociodemographic and clinical data. To determine the association between a priori selected sociodemographic variables, which are known to predict the use of psychological support, distress, and intention, we performed a multinomial logistic regression analysis. To determine the association between intention and uptake, we performed a logistic regression analysis. Results were presented as odds ratios with 95% confidence intervals. The level of significance was set at $P < .05$. Analyses were conducted by using SPSS Statistics version 22.0 (IBM, Armonk/NY, 2013).

2.5.2 | Qualitative analyses

We used content analysis to examine reasons for uptake of the psychooncology service.[31] This standardized, inductive approach analyzes qualitative data descriptively, adding a level of interpretation.[32] To guarantee high-quality content analyses, a team of trained researchers (AG, DZ, and TT) discussed the patients' reasons in a multistep procedure. First, we read the answers of the patients several times, divided the participants' answers into single reasons, and collected ideas about categories. Second, we gathered categories in a sample of 60 patients and refined them through an iterative process. Third, we coded reasons of all patients into categories, discussed inconsistence of assignment until consensus was reached, and assessed interrater- reliability by using Cohen kappa statistics (κ). Additionally, we identified main themes across categories. Analyses were conducted by using MAXQDA software version 12.2.0 (VERBI Software, Berlin, 2016).

3 | RESULTS

3.1 | Participant characteristics

Of 1240 outpatients who attended the clinic during 2013 to 2016 for an outpatient consultation, 484 were ineligible because of no further consultation, not being fluent in German, or being physically or cognitively impaired. Of all patients who attended the clinic, 756 (61%) were eligible for inclusion (Figure S1). In total, n = 333 patients completed the study (Table 1).

TABLE 1 Participants' sociodemographic and clinical characteristics

Participants (n = 333), Unless Otherwise Stated	n	%
Age, in Years		
Mean (SD)	60.5 (14.0)	
Range	19-93	
Sex		
Female	151	45.3
Male	182	54.7
Education		
Low (9th grade or less)	31	9.3
Middle (apprenticeship/high school)	186	55.9
High (diploma/university degree)	116	34.8
Living with a partner		
Yes	233	70.0
No	100	30.0
Living with children		
Yes	72	21.6
No	261	78.4
Distress thermometer[a]		
DT score 0-4	132	46.5
DT score 5-10	152	53.5
Time after initial cancer diagnosis, in weeks		
Median (range)	4 (0-264)	
Cancer type[b]		
Breast cancer	67	20.1
Thoracic malignancies	59	17.7
Hematologic malignancies	51	15.3
Genitourinary cancer	28	8.4
Melanoma/skin cancer	27	8.1
Gastrointestinal (noncolorectal) cancer	22	6.6
Central nervous system tumors	16	4.8
Others	64	19.2
Treatment approach		
Palliative	128	38.4
Curative	205	61.6
Current treatments (multiple treatments possible)		
Systemic treatment[c]	298	89.5
Radiotherapy	109	32.7
Surgery	34	10.2
No treatment/watch-and-wait/others	21	6.3

Abbreviations: SD, standard deviation; DT, Distress Thermometer.

[a]n = 284, DT from n = 49 patients missing due to nondelivery of the DT by clinical staff (n = 18), not being provided by patients (n = 22), and lost documents (n = 9).

[b]One participant with 2 cancer types.

[c]Systemic treatment includes chemotherapy, immunotherapy, hormone therapy, and targeted therapy.

3.2 | Distress, intention, and uptake of the psychooncology service

Of all participants, 53.5% showed high levels of psychosocial distress (DT ≥ 5); distress was normally distributed among all participants. Overall, 83 patients (25%) intended to use the psychooncology service (yes), 111 patients (33%) were ambivalent (maybe), and 139 patients (42%) did not intend to use the service (no). We found high distress scores (DT ≥ 5) in 71% of patients with yes, 56% of patients with maybe, and 42% of patients with no intention. After 4 months, 77 patients (23%) had used the service at least once (54 with yes intention [65% of all yes], 13 with maybe intention [12% of all maybe], and 10 with no intention [7% of all no]). Figure 1 shows distributions of uptake stratified according to levels of distress and intentions.

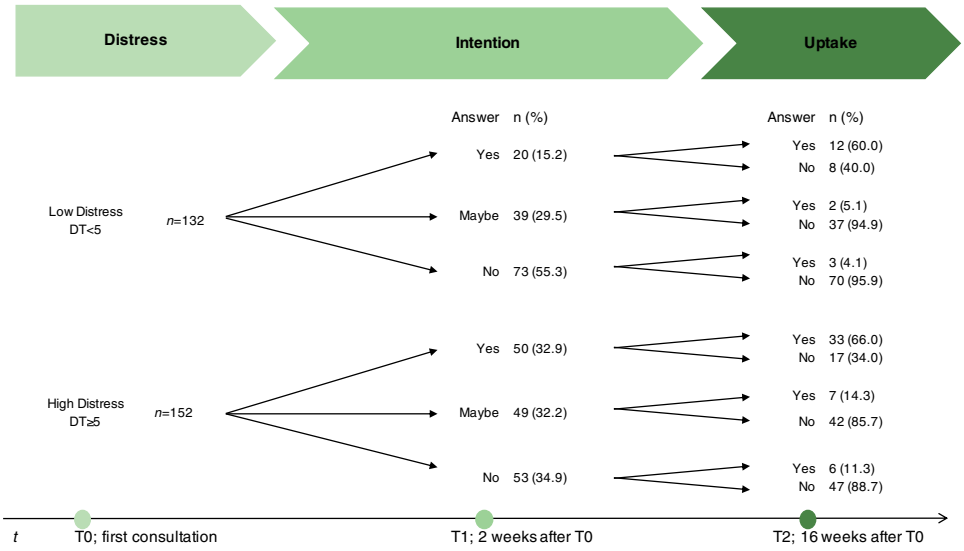

FIGURE 1 Description of patients' distress, intention, and uptake by distress level. Abbreviations: DT, Distress Thermometer; T0, screening; T1, baseline; T2, follow-up

In a multinomial logistic regression, patients with yes intention and patients with maybe intention were significantly more distressed than patients with no intention (yes: mean = 5.8 [SD = 2.4]; maybe: mean = 5.0 [SD = 2.6]; no: mean = 3.9 [SD = 2.7]). Age, sex, and education did not differ between intention groups (Table 2A). In a logistic regression analysis, patients with maybe and no intention showed significantly lower uptake behavior than patients with yes intention (Table 2B). This result did not materially change after adjustment for sociodemographic variables (data not shown).

3.3 | Reasons for yes, maybe, or no intention

Patients gave a total of 734 reasons, averaging 2.2 reasons per patient (min. 1, max. 6 reasons). Content analysis identified 32 categories of

TABLE 2 Associations among sociodemographic variables, distress, and intention as well as intention and uptake

(A) Multinomial Regression Analysis of Sociodemographic Variables and Distress on Intention									
	Intention Yes vs No[a]			Intention Maybe vs No[a]			Intention Yes vs Maybe[b]		
	B (SE)	OR [95% CI]	*P* Value	*B* (SE)	OR [95% CI]	*P* Value	*B* (SE)	OR [95% CI]	*P* Value
Distress (DT 0-10)	0.28 (0.06)	1.32 [1.17-1.49]	<.001**	0.17 (0.06)	1.18 [1.06-1.32]	.003*	0.11 (0.06)	1.12 [0.99-1.26]	.078
Age	−0.02 (0.01)	0.98 [0.96-1.00]	.107	−0.01 (0.01)	0.99 [0.97-1.01]	.406	−0.01 (0.01)	0.99 [0.97-1.01]	.410
Sex (0 = male, 1 = female)	0.19 (0.32)	1.21 [0.65-2.24]	.553	0.20 (0.29)	1.22 [0.69-2.14]	.497	−0.01 (0.33)	0.99 [0.52-1.88]	.980
Education (0 = low, 1 = high)	−0.14 (0.33)	0.87 [0.46-1.66]	.672	−0.11 (0.30)	0.90 [0.50-1.62]	.722	−0.03 (0.34)	0.97 [0.50-1.88]	.924

(B) Logistic regression analysis of intention on uptake			
	B (SE)	OR [95% CI]	*P* Value
Intention yes vs no[a]	3.18 (0.40)	24.02 [10.95-52.71]	<.001**
Intention maybe vs no[a]	0.54 (0.44)	1.71 [0.72-4.07]	.22
Intention yes vs maybe[b]	2.64 (0.37)	14.04 [6.74-29.24]	<.001**

Note. (A) Model χ^2 (8) = 28.94, P < .001, n = 284, Nagelkerke R^2 = 0.110. Education was dichotomized into "low/medium" (less than ninth grade/apprenticeship/high school) and "high" (diploma/university degree). (B) Model χ^2 (2) = 100.66, P < .001, n = 333, Nagelkerke R^2 = 0.395.

Abbreviations: *B*, Beta coefficient; SE, standard error; OR, odds ratio; CI, confidence interval; *P* value, significance level; DT, Distress Thermometer.

[a]Reference group *no* intention.

[b]Reference group *maybe* intention.

*P < .05.

**P < .001.

TABLE 3 Ranking order of categories of reasons for patients' (yes/maybe/no) intention to use the psychooncology service (n = 333)

Intention									
Yes (n = 83)			Maybe (n = 111)			No (n = 139)			
Rank	Categories	% (n)	Rank	Categories	% (n)	Rank	Categories	% (n)
1	[ATT1] Yes/psychooncologist is an expert	40% (33)	1	[DIS1] Maybe/fear of deterioration	46% (51)	1	[SUP2] No/social support (family and/or friends)	45% (62)
2	[COP1] Yes/support as means for empowerment and self-help	30% (25)	2	[SUP2] No/social support (family and/or friends)	25% (28)	2	[DIS8] No/subjective emotional and physical well-being	33% (46)
3	[DIS1] Yes/fear of deterioration	25% (21)	3	[DIS8] No/subjective emotional and physical well-being	24% (27)	3	[ATT9] No/psychologists are not helpful	19% (27)
4	[COP4] Yes/information and counseling	19% (16)	4	[DIS5] Maybe/uncertainty of current situation	14% (16)	4	[COP10] No/self-determination	19% (26)
5	[DIS2] Yes/bad news/shock	18% (15)	5	[DIS2] Maybe/bad news/shock	12% (13)	5	[COP9] No/self-management	14% (20)
6	[ATT6] Yes/recommendation	13% (11)	5	[ATT7] No/information is helpful and sufficient	12% (13)	6	[DIS7] No/favorable prognosis	13% (18)
7	[COP2] Yes/talking as catharsis	12% (10)	6	[DIS3] Maybe/uncertain medical situation	10% (11)	7	[SUP1] No/physician as main supporting partner	12% (16)
8	[ATT2] Yes/become acquainted with the psychooncologist	11% (9)	7	[COP9] No/self-management	9% (10)	8	[DIS1] Maybe/fear of deterioration	11% (15)
8	[COP5] Yes/disburden family	11% (9)	7	[COP4] Yes/information and counseling	9% (10)	9	[COP8] No/talking is not helpful	10% (14)
8	[DIS4] Yes/burdened family	11% (9)				10	[COP7] No/positive thinking	9% (13)
9	[ATT4] Yes/positive experience with psychological support	10% (8)						

Note. Categories are only listed above 9% of patients reporting (all categories are shown in Table S1). %, percentage of patients in this group reporting this category.

patients' reasons and 4 main themes. Interrater reliability was strong to moderate (κ = 0.70-0.89).[33] Table S1 contains a detailed description of all categories and number of reasons per group.

Four main themes emerged across groups: attitude (ATT), coping (COP), distress (DIS), and support (SUP). *Attitude* includes categories that describe patients' opinions about psychooncological support. *Coping* includes different strategies that patients say they used to handle a situation. *Distress* consists of several categories that describe either subjective distress or well-being as a reason for uptake or decline of support. Formal and informal support includes categories that describe support needs of patients.

Patients with a yes intention wanted to consult psychooncologists mainly because (1) they considered the psychooncologists to be experienced experts [ATT1], (2) they wanted support for self-empowerment [COP1], and (3) they wanted to prepare for potential physical or mental deterioration [DIS1]. Patients with no intention generally (1) felt supported enough by family and friends [SUP2], (2) reported mental and physical well-being [DIS8], and (3) did not think psychological support would be helpful [ATT9]. Ambivalent patients (maybe) combined reasons for and against support, and they often described a potential situation in which they would consider taking advantage of support services (ie, if-then thinking): (1) They wanted to use support if their physical or mental condition deteriorated [DIS1], (2) they currently felt supported enough [SUP2], and (3) they felt physically and emotionally well [DIS8]. Other reasons are listed in order of rank in Table 3 and Table S1.

4 | DISCUSSION

To the best of our knowledge, this study is the first longitudinal, observational study with prospective data along the distress screening pathway assessing cancer patients' distress, intention, and uptake of the psychooncology service focusing on patients' intentions by using mixed methods.

Our study had 3 key findings. First, with a trichotomous assessment of health-care service needs (yes/maybe/no), we identified a considerable number of ambivalent patients (33%), who had high mean distress levels but were less likely to use services. Second, we found an association between level of distress and patients' intentions, but 67% of patients with a high distress level did not intend to use support immediately. Third, qualitative analyses revealed different motives of ambivalent patients and patients with no or yes intention.

In line with previous research,[13,15,22,34] we found that the level of distress, but not age, sex, or education, was associated with the intention to use psychooncological support. However, about 35% of patients with high distress levels did not intend, whereas 45% of patients with low distress levels intended or maybe intended to use support. The general assumption that high distress equates with a need for support is based on a diagnostic model that recognizes patients who are at risk for mental disorders.[20,35] Predefining a cut-off value is a normative standard helpful for screening, but it must be used carefully, because we screen for *normative need* but not, per se, for patients' *felt* or *expressed needs*.[20]

Intention predicted uptake behavior, but 7% of patients with no intention used the service, and 35% of patients with an intention had not used the service after 4 months. Uptake behavior in ambivalent patients was low (12%). Further studies need to explore the barriers between intention and uptake.[18]

In the interview, patients with *no* intention emphasized social support and well-being, which supported our quantitative result on low distress values and aligned with previous research on highly distressed patients who declined support.[10] Patients' negative attitudes about psychological support and their strong emphasis on self-determination and self-management may indicate a patient concept avoiding help-seeking behavior, which is common in mental health-care settings.[10]

Similarly, positive attitudinal aspects, knowledge, and coping concepts were important for patients with an intention (yes). Attitudinal aspects and knowledge are relevant to support-seeking behavior.[24,36,37] Many of these patients had precise ideas of what they wanted and would get when asking for psychooncological support, which indicates that mental health literacy, knowledge, and patient empowerment is an important aspect for service use.[8,25]

However, attitudes, experiences, or knowledge about support services played a negligible role for most ambivalent patients (maybe). Ambivalent patients stated reasons for and against support: Fears and uncertainties were described as well as resources and well-being. Patients reported a lot of if-then thinking and seemed to be open to using the service at a later stage. In our clinical experience, a clear treatment plan, medical appointments, and a focus on going through the medical treatment psychologically stabilize patients. Dekker et al[38] argued that an increased distress level might indicate "adaptive emotional responses, which facilitate coping with cancer" instead of a maladaptive process. Further studies are needed.

Our study offers a novel, in-depth qualitative analysis of patients' supportive care needs, which revealed a threefold intention (yes/maybe/no) and a divergent pattern of motives for declining psychooncological support. Intention is relevant here because 67% of highly distressed patients did not want to make immediate use of the psychooncology service, but only 35% of these had no intention, and 32% were ambivalent (maybe).

Our study has several strengths. First, to our knowledge, it is the first study to monitor uptake behavior of patients after expressing supportive care needs in a longitudinal study. Second, we qualitatively analyzed patients' needs, a crucial extension of previous studies. Third, we assessed a large sample of cancer patients in the early phase of treatment with equal representation of men and women.

5 | STUDY LIMITATIONS

Our limitations are as follows: First, due to the large number of study participants, we decided against audio records. Instead, we used the qualitative method of taking notes during the interview and writing reflective postscripts afterward.[29] We countered possible interviewer bias by relying on a detailed interviewer manual and closely supervising interviewers. Second, this was a single center study. Our sample was representative for our clinic and other outpatient oncological settings that use a stepped-care model and integrate psychooncological

care (eg, Comprehensive Cancer Centers). Third, oncologists did not inform 13% of all eligible patients about the study, 28% of eligible patients did not want more information about the study, and 12% refused to participate after being informed. We adopted a recruitment strategy where the consultant oncologist recruited the patients because it offered several advantages. Oncologists are the first and closest contact for outpatients, it is a naturalistic setting, and being invited by a physician to participate in a psychooncological study might reduce the stigma to accept the invitation. But there is also a risk of bias if oncologists are more inclined to inform interested, approachable patients about the study, or to invite patients with spare time, or who they judged healthy enough to participate.

6 | CLINICAL IMPLICATIONS

It is essential to integrate patients' supportive care needs into the clinical distress screening pathway. Patients with an ambivalent intention to use support might go unrecognized in clinical practice because supportive care needs are usually captured with a dichotomous response format.[13] We propose to assess the supportive care needs of patients by using a trichotomous response format (yes/maybe/no) at the same time as assessing psychosocial distress with the DT. The needs of highly distressed patients who do not intend to use support services (no) might be better met if approaches to these patients focused on reducing stigmatization and enhancing self-determination. In contrast, it might be better to address the needs of highly distressed, ambivalent patients (maybe) by taking an "if-then" approach to discussions about service uptake. Taking the right approach to meet the needs of each patient group could optimize psychooncological health-care delivery. Supportive cancer care should also always include providing detailed information to all patients about the work psychooncologists do and the benefits of psychooncological treatments.

7 | CONCLUSION

Our study reveals patients' subjective needs linked to psychosocial distress and uptake of a psychooncology service in cancer outpatients by using mixed methods. We identified a vulnerable group of ambivalent patients. To optimize distress screening programs, we suggest that patients' supportive care needs should be addressed and discussed in routine clinical practice.

ACKNOWLEDGEMENTS

We thank all patients who gave us insight into their experiences and all oncologists for their time and commitment. We also thank our research team and colleagues for assisting with data collection and Claudia Steiner and Kali Tal for editing the language of the manuscript. This study was funded by the Swiss Cancer League (Berne, Switzerland), grant no KLS-3186-02-2013.

CONFLICT OF INTEREST

The authors declared no conflicts of interest. G.M. was a consultant for Janssen Research & Development, LLC.

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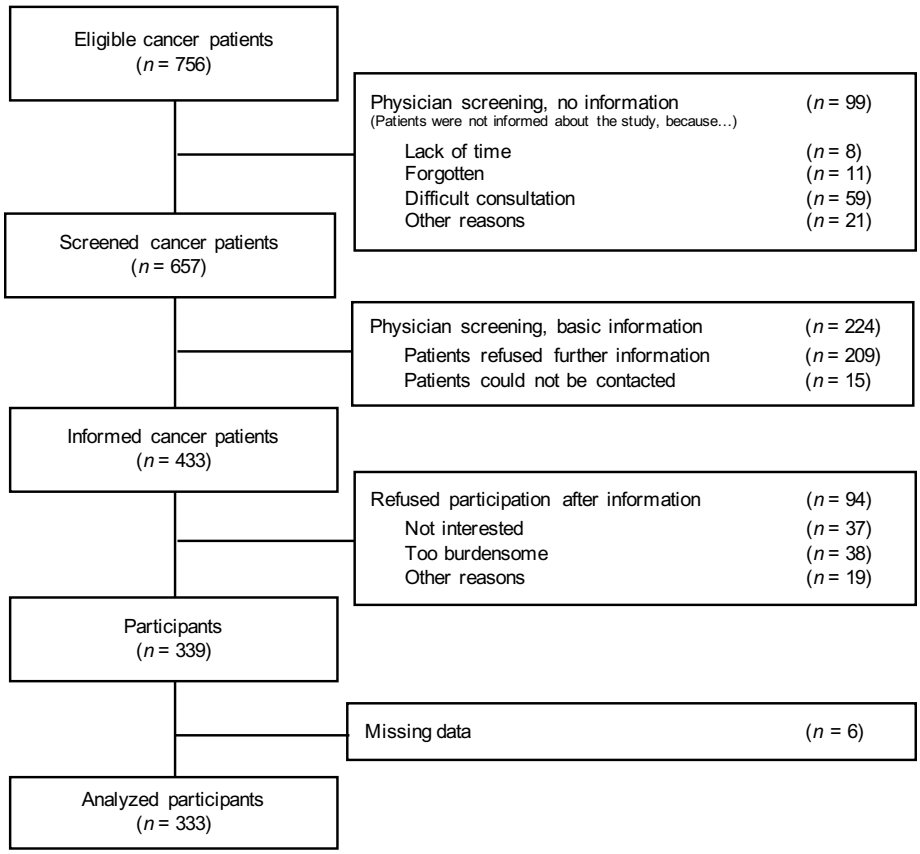
SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

How to cite this article: Tondorf T, Grossert A, Rothschild SI, et al. Focusing on cancer patients' intentions to use psychooncological support: A longitudinal, mixed-methods study. *Psycho-Oncology*. 2018;27:1656–1663. https://doi.org/10.1002/pon.4735

SUPPLEMENTARY



Supplementary Figure 1. Study flow

Supplementary Table 1. Overview of main themes and categories of participants' reasons for their (*yes/maybe/*no) intention to use the in-house psycho-oncology service. Participants supplied between one and six reasons.

Main themes	**Categories**	**Description**	**% (*n*) of patients reporting this category per group**		
Attitude [ATT]			***yes*** **(*n*=83)**	***maybe*** **(*n*=111)**	***no*** **(*n*=139)**
	[ATT1] Yes/ Psycho-oncologist is an expert	The psycho-oncologist is seen as an expert and/or a person with a professional neutral attitude who provides formal support.	40% (33)	6% (7)	-
	[ATT2] Yes/ Become acquainted with the psycho-oncologist	Patients want to get to know the psycho-oncologist.	11% (9)	4% (4)	-
	[ATT3] Maybe/ No concept of psycho-oncological support	Patients have no idea what psycho-oncologists do, or of the benefits of treatment.	2% (2)	4% (4)	-
	[ATT4] Yes/ Positive experience with psychological support	Patients have already had positive experiences with psychological and/or psycho-oncological support providers.	10% (8)	-	-
	[ATT5] Yes/ Psycho-oncological support as part of treatment	Patients see psychological support as part of comprehensive cancer treatment. They appreciate this interdisciplinary treatment.	6% (5)	-	-
	[ATT6] Yes/ Recommendation	A physician or a relative/ friend recommended the patient to take advantage of psycho-oncological support.	13% (11)	-	-
	[ATT7] No/ Information is helpful and sufficient	Patients say that it is helpful and sufficient to know a service exists, and that they can call on help on short notice.	-	12% (13)	3% (4)
	[ATT8] No/ Cost-benefit ratio	Patients report they have no time, must travel too long distances, or face other organisational or financial barriers. It requires too much effort to rearrange their daily lives and would be more costs than benefits.	-	6% (7)	7% (10)
	[ATT9] No/ Psychologists are not helpful	Patients think psychologists are not helpful. Some patients have a biomedical concept of illness and do not consider psychological aspects. Others have negative preconceptions or experiences with psychological support.	-	3% (3)	19% (27)
Total number of attitude [ATT] reasons per group			**68**	**38**	**41**

Main themes	Categories	Description	% (*n*) of patients reporting this category per group		
Coping [COP]			***yes*** **(*n*=83)**	***maybe*** **(*n*=111)**	***no*** **(*n*=139)**
	[COP1] Yes/ Support as means for empowerment and self-help	Patients think support can help them cope better with the disease, and will increase their own resources or improve their strategies. Psycho-oncological support is perceived as self-help.	30% (25)	-	-
	[COP2] Yes/ Talking as catharsis	Patients appreciate being able to talk with a psychologist and think they will be relieved when they do so.	12% (10)	-	-
	[COP3] Yes/ Finding meaning	Patients want to talk about the broader meaning of the disease, integrate the disease into their life story, make a life résumé, and find purpose.	8% (7)	-	-
	[COP4] Yes/ Information and counselling	Patients seek counselling for concrete and specific questions, including practical issues, advice on coping with a situation etc. Some patients report concrete expectations about what psychologists can offer (e.g., relaxation training).	19% (16)	9% (10)	-
	[COP5] Yes/ Disburden family	Patients do not want to burden their family and friends with their sorrows, so they seek professional help.	11% (9)	7% (8)	-
	[COP6] No/ Belief in God	The patient's religious faith compensates for, or replaces the need for psycho-oncological support.	-	2% (2)	1% (2)
	[COP7] No/ Positive thinking	Patients already have good coping strategies. They are optimistic, hopeful, and have positive thoughts about the future. They express hope and positive expectations.	-	7% (8)	9% (13)
	[COP8] No/ Talking is not helpful	Patients say they prefer not to talk about their situation and negative emotions.	-	6% (7)	10% (14)
	[COP9] No/ Self-management	Patients prefer to manage on their own. They have coping strategies that work well for the moment and they rely on their experience. They might consider seeking support later.	-	9% (10)	14% (20)

	[COP10] No/ Self-determination	Autonomy and self-determination in handling the situation is paramount. Seeking psycho-oncological support would be a sign of mental weakness. These patients believe that nobody can carry the burden for them.	-	3% (3)	19% (26)
	[COP11] No/ Acceptance	Patients accept the situation. Some patients mention their advanced age and their acceptance of death. Some patients see dying as an integral part of life (independent of age).	-	-	7% (10)
Total number of coping [COP] reasons per group			**67**	**48**	**85**
Main themes	**Categories**	**Description**	**% (*n*) of patients reporting this category per group**		
Distress [DIS]			***yes* (*n*=83)**	***maybe* (*n*=111)**	***no* (*n*=139)**
	[DIS1] Yes or Maybe/ Fear of deterioration	Patients would consider using the psycho-oncology service if they physically or mentally deteriorate or if they have side effects from treatment.	25% (21)	46% (51)	11% (15)
	[DIS2] Yes or Maybe/ Bad news / shock	Patients report being very distressed by their cancer diagnosis. They want psychological support to cope with this shock/ crisis or consider relying on psycho-oncological support after receiving bad news (e.g. progression, recurrence of disease).	18% (15)	12% (13)	-
	[DIS3] Yes or Maybe/ Uncertain medical situation	Patients are uncertain about their medical situation. They either request support for decision making and handling uncertainty, or they postpone deciding whether or not to use support because of the uncertainty.	4% (3)	10% (11)	-
	[DIS4] Yes/ Burdened family	Patients say their family/ spouse/ children are burdened and that the psycho-oncologist could support them as a couple, family etc.	11% (9)	3% (3)	-
	[DIS5] Maybe/ Uncertainty of current situation	Patients cannot now decide if they want to use the service in the future.	-	14% (16)	-
	[DIS6] No/ Feeling unwell	Patients say they cannot see the psychologist because they first have to deal with their physical problems. They report pain or fatigue and do not feel well enough to see a psycho-oncologist.	-	4% (4)	-

	[DIS7] No/ Favourable prognosis	Patients think their cancer is curative or has a favourable prognosis and therefore do not want or need psychological support.	-	2% (2)	13% (18)
	[DIS8] No/ Subjective emotional and physical well-being	Patients say that because they feel mentally and physically well, they do not need psycho-oncological support.	-	24% (27)	33% (46)
Total number of distress [DIS] reasons per group			**48**	**127**	**79**
Main themes	**Categories**	**Description**	**% (*n*) of patients reporting this category per group**		
Support [SUP]			***yes* (*n*=83)**	***maybe* (*n*=111)**	***no* (*n*=139)**
	[SUP1] No/ Physician as main supporting partner	Patients think the medical information and support they receive from physicians is comprehensive and sufficient. Most of these patients have a biomedical care concept.	-	6% (7)	12% (16)
	[SUP2] No/ Social support (family and/or friends)	Patients report enough social support from family, friends, colleagues, or employer, and prefer to receive support from these sources. They do not perceive a need for more professional psycho-oncological support.	-	25% (28)	45% (62)
	[SUP3] No/ Other psychosocial support	Patients already have or prefer other professional psychosocial support options (e.g., social worker, pastoral care, alternative medicine hospitals, cancer support organisations).	-	4% (4)	3% (4)
	[SUP4] No/ External psychological support	Patients already get external psychological, psychotherapeutic, psycho-oncological or psychiatric support and do not need support at the hospital.	-	-	9% (12)
Total number of support [SUP] reasons per group			**0**	**39**	**94**
Total number of all reasons			**183**	**252**	**299**

Note. *n*, number of patients.

4.2 Oncologist Recommendation Matters! - Predictors of Psycho-Oncological Service Uptake in Oncology Outpatients

Received: 26 August 2018 | Revised: 10 November 2018 | Accepted: 15 November 2018

DOI: 10.1002/pon.4948

PAPER

WILEY

Oncologist recommendation matters!—Predictors of psycho-oncological service uptake in oncology outpatients

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Funding information
Swiss Cancer League, Grant/Award Number: KLS 3186-02-2013

Abstract

Objective: Highly distressed cancer patients often do not use psycho-oncological services (POS). Research on predictors of POS uptake has mainly focused on patient-related variables and less on communication variables, so we examined the link between patient-oncologist communication (ie, talking about psychosocial distress, providing detailed information, and recommending POS) and POS uptake.

Methods: We conducted a prospective, observational study in an Oncology Outpatient Clinic in Switzerland. Predictors (ie, patient-related variables and patient's reports of the patient-oncologist communication) were assessed via semistructured interviews, and information on outpatient POS uptake was assessed after 4 months. For statistical analysis, a multivariate logistic regression was performed.

Results: Of 333 participants (mean age 61 years; 55% male; 54% distress thermometer ≥5), 77 (23%) had used POS during a 4-month period. Patients who reported an oncologist-recommended POS (odds ratio [OR] = 6.27, 95% confidence interval [CI] = 3.14-12.85) and those who were not sure if they had received a recommendation (OR = 4.64, 95% CI = 1.83-11.97) were more likely to attend POS than those who reported receiving no recommendation. Talking about psychosocial distress (OR = 0.74, 95% CI = 0.38-1.46) and providing detailed information about POS did not predict POS uptake (OR = 1.06, 95% CI = 0.46-2.38).

Conclusions: Oncologists' expert recommendations to attend POS were strongly associated with patients' uptake of POS. The central role played by oncologists should be accounted for in stepped psycho-oncological care when POS referral pathways are defined.

KEYWORDS

cancer, distress, patient-physician communication, predictors, psychological support, psycho-oncology, recommendation, referral pathway, stepped care, utilization

Antje Frey Nascimento and Theresa Tondorf contributed equally to this work.

1 | BACKGROUND

Psychosocial distress and mental disorders are common among cancer patients[1,2] and should be addressed by psycho-oncological interventions to improve quality of life and reduce emotional distress.[3,4] Routine distress screening tools implemented in oncological practice can identify patients with elevated psychosocial distress so they can be referred to psycho-oncological services (POS),[5] but 50% to 71% of patients with clinically significant levels of psychosocial distress do not use POS.[6,7] Increasing adequate referral and usage of POS by distressed patients and offering the support needed are a challenge in psycho-oncological care delivery.[8,9]

Although elevated psychosocial distress is positively associated with POS uptake,[10-12] distress level is not the only factor associated with patient uptake of POS.[13,14] Other factors also predict uptake, including patient-related characteristics like younger age,[10,12,15] female gender,[10-12,15] higher education,[15-17] and factors associated with the oncological treatment.[15,18,19] These patient-related characteristics cannot be modified. However, it is possible to design interventions that target modifiable contextual aspects along the distress screening pathway, including key aspects of patient-oncologist communication after distress screening, to better manage patient distress.[20]

So far, we know that patient-oncologist communication during the distress screening process might be positively linked to patients' uptake behaviour and lead to more adequate referral to POS.[8,21] Singer and colleagues[22] found that a stepped care model in which patients and oncologists discussed distress screening results decreased referrals in patients without psychiatric comorbidities and increased referrals in patients with psychiatric comorbidities compared with the standard care model without a discussion. Some studies have suggested that informing patients about the availability and benefits of psychological support and providing them with practical information about psycho-oncological treatment may increase uptake of services.[9,10,17,23] There is also evidence that most patients would accept a recommendation to use POS by their physician[16] and that lack of a recommendation by health care providers can be a barrier to POS uptake.[24] Improving patient-oncologist communication after distress screening is important because it may facilitate patients' understanding, reduce uncertainty, help patients to make informed decisions about their care, and increase satisfaction with care.[23,25-27] As far as we know, no study examined the association between various specific communication variables in the patient-oncologist communication after distress screening and POS uptake in a large outpatient population from the patient perspective.

We hypothesized that three patient-oncologist communication variables (*talking*, *informing*, and *recommending*) and previously identified patient-related characteristics (younger age, female gender, higher education level, palliative treatment intent, and higher psychosocial distress) would be positively associated with POS uptake. In more detail, patient-oncologist communication variables were (*a*) talking, during which the oncologist addressed the patients' individual psychosocial distress; (*b*) informing, referring to detailed information about the availability of POS provided by the treating oncologist; and (*c*) recommending, reflecting the fact that the oncologist provided a recommendation to attend POS.

2 | METHODS

2.1 | Participants and setting

Data are based on a prospective, observational study conducted in the Oncology Outpatient Clinic of the University Hospital Basel (Switzerland). In Switzerland, POS is available at most hospitals with oncological centres, and costs are covered by basic health insurance. In these institutions, POS is available on short notice by self-referral or referral of a physician. Psychotherapeutic support outside of the hospitals is provided by psychotherapists in private practice and associated with waiting lists, and costs that are not covered by basic insurance in every case. Methods of the study have been described earlier.[28] Cancer outpatients who presented for the first time at the outpatient clinic between October 2013 and January 2016 were eligible if they were ≥18 years old, fluent in German, not cognitively or physically impaired in a way that impeded participation, and were scheduled for at least one more outpatient consultation with an oncologist at the clinic.

2.2 | Standard screening procedure

Based on a stepped psycho-oncological care model,[29] all patients were routinely screened for psychosocial distress with the distress thermometer (DT) before their first outpatient consultation with the oncologist and were given written information about the outpatient POS. Screening for psychosocial distress is standard procedure for new patients at the Oncology Outpatient Clinic and independent of study participation. Oncologists were told to address the patient's psychosocial distress level in the first consultation. They were advised to recommend the POS to patients who reported high distress levels (DT ≥ 5), as well as based on their clinical judgment, or the patient's request. The actual referral to the POS was guided by patients' consent. Oncologists participated in a 1-hour training that taught them how to communicate about psychosocial distress and how to follow guidelines for referring patients to POS.

2.3 | Study procedure

Treating oncologists informed cancer patients about the study after the first consultation to ascertain their interest in study participation. Thereafter, the study team informed eligible and interested patients about the study procedure in detail, obtained informed consent, and interviewed participants after the first outpatient consultation (average time to interviews was 15 days, and ranged from 0 to 46 days). Semistructured interviews on the phone or face to face were conducted in German. Prompts and reflections were used to encourage patients to talk and to elicit detail where necessary. Interviewers (TT, AFN, and six further Master's level students) used an interviewer manual and were closely supervised by a psycho-oncologist and trained researcher (DZ). The local ethics committee approved the study (Ethikkommission Nordwest-und Zentralschweiz, Ref. No.: EK220/13), which complied with the Declaration of Helsinki.

2.4 | Measures

2.4.1 | Outcome variable

POS uptake was defined as having attended at least one appointment at the Outpatient Psycho-oncology Service at the University Hospital Basel within 4 months after entering the study (yes/no). Data on POS uptake were prospectively retrieved from hospital records.

2.4.2 | Predictor variables

Patients' sociodemographic and clinical data

Patients' sociodemographic data (age, gender, education) were recorded during the interview; clinical data on patients' oncological treatment (treatment intent) were collected from their medical records.

Psychosocial distress

The German version of the National Comprehensive Cancer Network distress thermometer was applied to screen patients for psychosocial distress.[30] The reliable and validated screening tool has one item ("Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today"). A score of ≥5 on the DT (from 0 "no distress" to 10 "extreme distress") indicates clinically significant levels of psychosocial distress. Psychosocial distress was also assessed in the interview with the question, "How much distress have you been experiencing in the past week including today on a scale from 0 "no distress" to 10 "extreme distress?"

Patients' report of the communication with the oncologists

They were asked (*a*) talking: "Did the oncologist talk about your psychosocial distress with you?" (answers: yes/no/do not know), (*b*) informing: "Did the oncologist inform you about how the psycho-oncologist can provide support?" (answers: yes/no/do not know), and (*c*) recommending: "Did the oncologist recommend that you attend the psycho-oncology service?" (answers: yes/no/do not know).

2.5 | Data analyses

We descriptively analysed sociodemographic, clinical, and communication-related variables. Education was dichotomized into "academic" (based on a university degree) and "nonacademic" (based on high school, apprenticeship, or no education). Patients whose DT scores were missing (due to n = 18 nondelivery by clinical staff; n = 22 not provided by patients; n = 9 lost documents) were assessed for distress during the interview, and DT values were replaced by interview distress values in the analysis. To estimate predictors of POS uptake, we used uptake as outcome variable (*no* uptake as reference group) in a multivariate logistic regression analysis. Patient-related variables known to predict POS uptake (including age, gender, education, oncological treatment intent, and psychosocial distress) were selected a priori. We also entered the three communication variables (*talking*, *informing*, and *recommending*) with two dummy variables each (*yes* vs *no*; *do not know* vs *no*) and used *no* as reference category. We then tested the interaction of perceived recommendations with distress. Additionally, to measure the effect of the communication variables only, we calculated a multivariate logistic regression analysis using all communication variables as predictors of POS uptake. We present results as odds ratios (OR) with 95% confidence intervals (95% CI). To evaluate the goodness of fit and predictive accuracy of the model, we calculated Nagelkerke's R^2 and the C-statistic. We used "R" (R Foundation for Statistical Computing, Vienna/Austria, 2008) to analyse the data.

3 | RESULTS

3.1 | Participant and oncologist characteristics

Of 1240 patients who attended the clinic for an outpatient consultation during the study period, 756 (61%) were eligible for inclusion (Figure S1, study flow). Of 1240 outpatients who attended the clinic during 2013 to 2016 for a consultation, 484 patients were ineligible because of no further consultation (n = 195), not being fluent in German (n = 164), or being physically or cognitively impaired (n = 125). Table 1 shows sociodemographic and clinical characteristics of 333 patients who completed the study (44% of eligible patients; 44% on the phone, 56% face to face). Mean age was 61, 55% were men, mean distress score was 4.7 (SD = 2.7), and 54% showed high levels of psychosocial distress (DT ≥ 5). After 4 months, 77 patients (23%) had used the POS. Twenty-five oncologists participated in the study. Mean age was 36 (range 28-58 years), 13 were men, and professional seniority ranged from 0 to 30 years. They were 9 senior oncologists (professional seniority ≥6 years), 6 oncologists in training (professional seniority ≤4 years), and 10 resident oncologists (professional seniority ≤2 years).

3.2 | Patients' report of the patient-oncologist communication

More than half of the patients (54%) recalled talking with the oncologist about psychosocial distress, 17% recalled receiving detailed information about the POS (Table 2). Frequencies of talking and informing were similar in patients with low and high distress (Table 2). However, almost twice as many patients with high distress (30%) than patients with low distress (16%) said they were given a recommendation for POS.

3.3 | Predictors of POS uptake

The multivariate logistic regression analysis (Table 3) showed that patients who reported receiving a recommendation from their oncologist (recommending: yes) and patients who were not sure if they received a recommendation (recommending: do not know) were more likely to attend the POS than patients who did not report a recommendation from their oncologist in the first consultation (recommending: no). Younger patients, patients with high distress values, and patients with high education were more likely to attend

TABLE 1 Sociodemographic and clinical characteristics of participants (n = 333, unless otherwise stated)

	n (%)
Age, in years	
Mean (SD)	60.5 (14.0)
Range	19-93
Gender	
Female	151 (45.3)
Male	182 (54.7)
Education	
Nonacademic	217 (65.2)
Academic (diploma/university degree)	116 (34.8)
Distress thermometer[a]	
DT score 0-4	132 (46.5)
DT score 5-10	152 (53.5)
Oncological treatment intent	
Palliative	128 (38.4)
Curative	205 (61.6)
Time after initial cancer diagnosis, in weeks	
Median (range)	4 (0-264)
Cancer type[b]	
Breast cancer	67 (20.1)
Thoracic malignancies	59 (17.7)
Hematologic malignancies	51 (15.3)
Genitourinary cancer	28 (8.4)
Melanoma/skin cancer	27 (8.1)
Gastrointestinal (noncolorectal) cancer	22 (6.6)
Central nervous system tumours	16 (4.8)
Others	64 (19.2)
Current oncological treatments (multiple treatments possible)	
Systemic treatment[c]	298 (89.5)
Radiotherapy	109 (32.7)
Surgery	34 (10.2)
No treatment/watch and wait/others	21 (6.3)

Abbreviations: SD, standard deviation; DT, distress thermometer.

[a]n = 284, DT information from 49 patients were missing due to nondelivery of the DT by clinical staff (n = 18), not being provided by patients (n = 22), and lost documents (n = 9).

[b]One participant with two cancer types.

[c]Systemic treatment includes chemotherapy, immunotherapy, hormone therapy, and targeted therapy.

TABLE 2 Frequencies of patient's reports of the patient-oncologist communication in all patients (n = 333) and in subgroups of high distressed (n = 152) and low distressed (n = 132) patients

		All Patients (n = 333)	High Distressed Patients (n = 152)	Low Distressed Patients (n = 132)
	Answer	n (%)	n (%)	n (%)
Talking	Yes	179 (54%)	80 (53%)	73 (55%)
	Do not know	38 (11%)	18 (12%)	14 (11%)
	No	116 (35%)	54 (36%)	45 (34%)
Informing[a]	Yes	58 (17%)	29 (19%)	21 (16%)
	Do not know	95 (29%)	43 (28%)	40 (30%)
	No	179 (54%)	79 (52%)	71 (54%)
Recommending[b]	Yes	75 (23%)	45 (30%)	21 (16%)
	Do not know	48 (14%)	21 (14%)	19 (14%)
	No	208 (63%)	86 (57%)	91 (70%)

Talking ("Did the oncologist talk about your psychosocial distress with you?"); informing ("Did the oncologist inform you about how the psycho-oncologist can provide support?"); recommending ("Did the oncologist recommend that you attend the psycho-oncology service?").

[a]1 missing answer.

[b]2 missing answers.

TABLE 3 Multivariate logistic regression analysis using patient-related variables (sociodemographic and clinical variables) and patient-oncologist communication variables (talking, informing, recommending) to predict POS uptake

	Wald	OR	95% CI	*P* Value
Communication variables				
Talking (yes vs no)	−0.87	0.74	0.38-1.46	0.387
Talking (do not know vs no)	0.38	1.21	0.45-3.13	0.701
Informing (yes vs no)	0.14	1.06	0.46-2.38	0.887
Informing (do not know vs no)	−1.16	0.62	0.27-1.37	0.245
Recommending (yes vs no)	5.13	6.27	3.14-12.85	<0.001**
Recommending (do not know vs no)	3.22	4.64	1.83-11.97	0.001**
Patient-related variables				
Age (per 10 years)	−2.31	0.78	0.63-0.96	0.021*
Gender (female)	−0.46	0.87	0.48-1.58	0.643
Education (high)	1.97	1.87	1.01-3.50	0.048*
Treatment intent (palliative)	0.78	1.27	0.69-2.33	0.437
Distress (per unit, 0-10)	3.99	1.28	1.14-1.45	<0.001**

n = 330, Nagelkerke's R^2 = 0.295, C-statistic = 0.80.

Abbreviations: POS, psycho-oncological service; B, beta-coefficient; SE, standard error; Wald, Wald-statistic; OR, odds ratio; CI, confidence interval; *P* value, significance level; R^2, Nagelkerke's R^2; C, C-statistic.

**P* value <0.05.

***P* value <0.01.

the POS. POS uptake was not predicted by a patient's report that the oncologist had discussed psychosocial distress of the patient (talking) or that the oncologist had given detailed information (informing) about the POS. Gender and oncological treatment intent (curative vs palliative) did not predict POS uptake. These associations did not change if only the three communication variables were included into the model (Table S1). We found no interaction effect between distress and oncologist recommendation (data not shown). There was no difference in POS uptake in higher compared to lower distressed patients reporting a recommendation from their oncologist.

4 | DISCUSSION

In this study, we examined predictors of POS uptake, focusing on variables of the patient-oncologist communication. As we hypothesized, patients who reported an oncologist recommendation were much more likely to use POS than patients who did not report an oncologist recommendation. Patients who were unsure if an oncologist gave

them a recommendation were also more likely to attend POS than patients who did not report an oncologist recommendation. Contrary to our hypotheses, patients who reported receiving detailed information about POS (informing) or who reported discussing their psychosocial distress (talking) were not more likely to attend POS. We found that high distress levels predicted POS uptake[10-12] along with age and educational level,[10,12,15-17] but found no association between female gender or palliative treatment intent and POS uptake.

First and importantly, we found a strong association between the report of an oncologist's recommendation for POS and uptake, controlling for patients' distress level. This finding suggests that the oncologist's judgment that psycho-oncological support is necessary for the patient considerably influences a patient's uptake of support. Patients might trust the oncologist's judgment since in German-speaking countries, oncologists are central in the referral of POS.[31] Moreover, it has been suggested that in the context of a life threatening disease the clinical relationship arises primarily from patients' appreciation of the clinicians' expertise in a phase of vulnerability. The intensity of the patient to clinician rapport after one meeting was shown to be strong.[32] Additionally, recommendations might carry more weight than complex information about what psycho-oncologists do or talking about individual distress because they are easier for patients to process. The semantic clarity an oncologist's recommendation provides may be particularly important in a first outpatient consultation, since these consultations typically are loaded with new and potentially stressful information. When patients are under emotional stress, their cognitive capacity to process and recall information in oncological consultations may diminish,[25,33,34] and the majority of patients in our study were under emotional stress prior to their first oncological consultation. Thus, distress levels in our study were higher compared with other studies.[16,18] However, in most studies, distress was not assessed prior to the first consultation but at home or at any time at the clinic.

We were surprised to find that patients who were unsure if they had received a recommendation from their oncologist were also more likely to use POS. It is possible that these patients were given a recommendation which influenced their choice, but could not remember it clearly in the interview.[35] It is also possible that the patients received a recommendation but could not remember if it came from the oncologist in the first consultation or from another source inside the clinic (eg, written information on the DT, nurses, other involved health care providers) or outside the clinic (eg, spouses, friends). Additionally, a patients' attitude towards POS might also affect their memory.[10,12,14] Patients with positive or rather neutral attitudes towards POS may be more able to recognize a recommendation from their oncologists. Patients with a more negative attitude towards POS will probably verbalize their psychosocial concerns and support needs less explicitly. Finally, oncologists may initiate discussions and provide referral more often if they perceive more explicit and more frequent cues of psychosocial concerns.[36] It should be emphasized that oncologists were instructed to treat all patients equally within the referral process, yet adapted information provision and recommendation to patients individually. Since a naturalistic interaction and a patient-tailored referral was the aim, there was also a certain latitude of oncologist behaviour in the referral pathway regarding recommendations.

Moreover, we found that patients who reported talking about psychosocial distress with their oncologist in the first consultation did not take advantage of POS more frequently. However, oncologists and patients may have different views of what it means to have talked about psychological distress. A study by Mackenzie et al[37] showed that almost half of the patients who did not want to talk about their distress with their oncologist said that other issues were more important to them in an oncological consultation, which aligns with our findings that only half of the patients in our study reported having a conversation about psychosocial issues during their consultation.

Further, we found that patients who reported having received detailed information about what psycho-oncologists do did not more frequently take advantage of POS. In fact, less than one-fifth of patients reported having received detailed information from their treating oncologist in the first consultation. Again, oncologists and patients might have different views of what detailed information about POS means, and the stressful situation may have affected patients' ability to process and recall this information.[33,34] Probably, the complexity of the information did not meet the situational need of the patient and patients may be more likely to remember detailed information about POS if it was disseminated in a later appointment.

Like previous studies, we found that high distress levels predicted POS uptake[10-12] as did patient characteristics like age and educational level.[10,12,15-17] Like some other studies, we found no association between gender and POS uptake.[38,39] POS uptake was also not associated with oncological treatment intent (curative vs palliative), that corresponds to other studies[18,19] which reported no association between treatment intent and wish for referral. We determined treatment intent from patients' medical records instead of asking patients for their perception, yet patients' perception of the treatment goal often differs from the oncologist's perception,[25] and we assume that the individual perspective of patients is key for patients' uptake behaviour. Furthermore POS uptake is not the unique or exclusive manner of addressing patients' distress. Patients may already have their individual coping mechanisms or self-management strategies which they prefer and may be more effective for them.[6] Therefore, a patient-oriented approach should be considered in stepped care systems to tailor support to patients' needs.

4.1 | Clinical implications

Our results indicate that in a stepped psycho-oncological care model in which oncologists triage patients, their expert recommendations strongly affect patients' decisions to use POS. Because of their influence, oncologists need to act sensitively and responsibly to help patients overcome barriers to use POS. Oncologists should take patient-related factors into account when making recommendations, and pay special attention to the needs of older patients and less educated patients because patients in these groups are less likely to take advantage of POS. Because giving patients detailed information about POS was not associated with POS uptake, it may be better to provide detailed information in later consultations. Giving information and discussing distress should not be omitted even though for the

analysed target (uptake) we do not have evidence of a predictive power. However, these two aspects are essential for the empowerment of patients and belong to a contemporary and comprehensive patient care. In any case, findings of the present analyses call for stronger interdisciplinary collaboration and demand further investigations of how patients experience communication with health care providers.

4.2 | Study limitations

Our study has several limitations. First, we have no objective record of the consultations and, thus, did not capture what happened between the patient and oncologist. We decided against audio or video recording because we would have had to include patients before their first visit and we expected this to cause major recruitment problems Social desirability, recall biases, and oncologist bias have to be considered as sources of bias of the reports.[25,40] The lack of objective records limits our understanding of what leads to patients to being unsure of whether or not an information had been given and how comprehensibly oncologists verbalized a recommendation and on what grounds. Because oncologists' workload and terms of employment were not comparable, we could not control for recommendation rate. However, in our study, we chose to focus on patients' subjective reports, which we consider key for their actual behaviour. Second, this is a monocentre observational study conducted at a Swiss comprehensive cancer centre, with cultural particularities regarding the strong position of the oncologist in the coordination of psychosocial care.[31] Hence, our centre might not represent other outpatient oncological settings that integrate POS into a stepped-care model where the treating oncologist generally addresses psychosocial issues.[22] However, our sample included a large gender-balanced sample of cancer patients, a broad array of cancer types, and the POS uptake rate was comparable to other outpatient oncological settings.[11] Third, due to ineligibility criteria, our findings are not representative for patients who are not fluent in German or who are cognitively and physically very impaired. Thirteen per cent of all eligible patients were not informed about the study, 28% of eligible patients refused information about the study, and 12% refused participation. Our recruitment strategy was designed to reduce the stigma of accepting an invitation to participate in a psycho-oncological study, but there is a risk of selection bias if oncologists informed only patients who were considered to be interested or healthier. Also, it is possible that patients who declined study participation are in general less interested in psychological content and would decline the usage of POS, that potentially could interfere with the representativeness of the enrolled patients. However, declining patients could also be psychologically too burdened but yet interested in POS offers. Taking ethical considerations into account we demanded two detailed interviews from patients in a vulnerable state of health. However, we were careful in seeking information and not overtaxing patients; the study team and all oncologists were sensitized to prioritize patients' health, and the study was carefully approved by the local ethics committee.

5 | CONCLUSION

Reported oncologists' expert recommendations to attend POS were strongly associated with patients' uptake of POS. The central role oncologists play for POS uptake should be accounted for in stepped psycho-oncological care when POS referral pathways are defined. Also, oncologists should pay attention to the needs of older patients and less well-educated patients. Because receiving detailed information about POS did not result in more POS uptake, it may be better to provide detailed information in later consultations.

ACKNOWLEDGEMENTS

We thank all patients who gave us insight into their experiences and all oncologists for their time and commitment. We also thank our research team and colleagues for assisting with data collection, namely, Sandra Basset, Silke Hogg, Luzia Inauen, Jael Mattmann, Milena Petignat, and Annik Schaad, and Claudia Steiner and Kali Tal for editing the manuscript. This study was funded by the Swiss Cancer League (Berne, Switzerland), Grant No. KLS-3186-02-2013.

CONFLICT OF INTEREST

GM was a consultant for Janssen Research & Development, LLC. All other authors declared no conflicts of interest.

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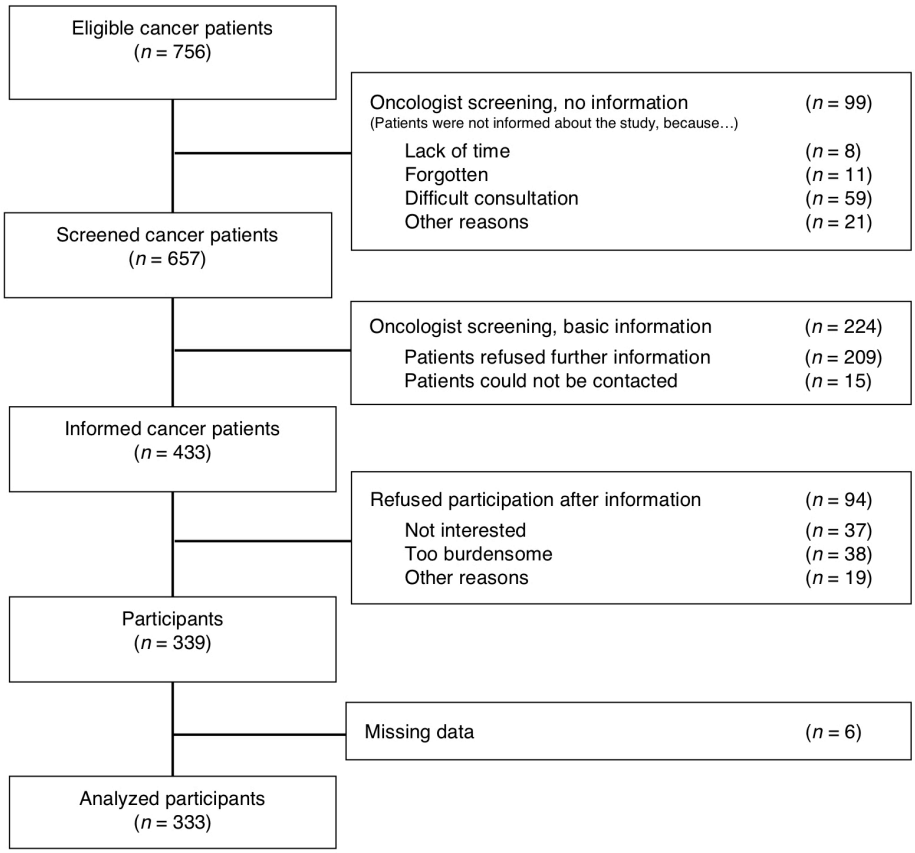
SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

How to cite this article: Frey Nascimento A, Tondorf T, Rothschild SI, et al. Oncologist recommendation matters!—Predictors of psycho-oncological service uptake in oncology outpatients. *Psycho-Oncology*. 2018;1–7. https://doi.org/10.1002/pon.4948

SUPPLEMENTARY



Supplementary Figure 1. Study flow

Supplementary Table 1. Multivariate logistic regression analysis using patient-oncologist communication variables (talking, informing, recommending) to predict POS uptake.

	B (SE)	Wald	OR	95% CI	*p*-value
Communication variables					
Talking (yes vs no)	-0.27 (0.3)	-0.84	0.76	0.40–1.44	0.402
Talking (don't know vs no)	0.04 (0.5)	0.08	1.04	0.40–2.55	0.933
Informing (yes vs no)	0.30 (0.4)	0.78	1.35	0.63–2.83	0.436
Informing (don't know vs no)	-0.41 (0.4)	-1.06	0.66	0.30–1.39	0.287
Recommending (yes vs no)	1.77 (0.3)	5.46	5.88	3.13–11.22	**<0.001****
Recommending (don't know vs no)	1.41 (0.4)	3.23	4.10	1.74–9.74	**0.001***

Note. *n*=330, Nagelkerke's R^2=0.170, C-statistic=0.73.

Abbreviations. POS, psycho-oncological service; B, Beta-coefficient; SE, standard error; Wald, Wald-statistic; OR, odds ratio; CI, confidence interval; *p*-value, significance level; R^2, Nagelkerke's R^2; C, C-statistic.

* *p*-value <0.05; ** *p*-value <0.01.

4.3 Talking about psychosocial distress screening: what oncologists and cancer patients recall

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Tondorf, T., Rothschild, S.I., Koller, M.T., Rochlitz, C., Kiss, A., Grossman, P., & Zwahlen, D. Talking about psychosocial distress screening: what oncologists and cancer patients recall. (under review in *Supportive Care in Cancer*)

Purpose. The aim of this study was to assess how oncologists use psychosocial distress screening procedures and to compare cancer patient and oncologist recall regarding communication about distress and support in clinical oncology. **Methods.** Patients were screened for psychosocial distress with the Distress Thermometer (DT) before their first consultation in an oncology outpatient clinic. Oncologists (*n*=25) discussed distress and support options with patients (*n*=333). After the consultation, oncologists used a questionnaire to evaluate the screening procedure and conversation. In a semi-structured interview, patients recalled their perceptions of the conversation. **Results**. Oncologists primarily used the DT in the first consultation to initiate communication about psychosocial distress. Whereas oncologists reported addressing distress during 96.6% of all consultations, 53.8% of the patients recalled any discussion of this topic. Higher age, greater distress, and attaching less importance to talking about distress with the oncologist predicted patients' failure to remember that distress had been addressed. Although oncologists reported providing detailed information about psycho-oncological support in 89.9% of consultations, 18.2% of the patients had any recollection of such information. Oncologists recommended 56.6% of patients to attend the psycho-oncology service, whereas 23.7% of the patients recalled a recommendation. **Conclusions.** Oncologists and patients differed substantially in recall of communication about psychosocial distress. Oncologists attempted to use the DT more to initiate communication about distress than as an assessment tool. However, patients often failed to register this communication. For an improved psychosocial care in oncology, distress-screening programs must consider new approaches to enhance patient-clinician communication. **Keywords**: cancer, distress screening, patient-clinician communication, psychosocial care, recall

INTRODUCTION

Psychosocial distress screenings are used in routine oncology practice to help clinicians rapidly identify cancer patients whose level of psychosocial distress is high, and to initiate referral to psychosocial services [1-3]. Screening programs have been implemented as an international standard for comprehensive care of cancer patients, and are mandatory for institutional certification as a Comprehensive Cancer Center in many countries [3-5]. However, the validity and usefulness of these screenings have been questioned in clinical practice [6, 7]. Clinical practice and research show that severity of distress is not the only factor influencing whether or not a patient accepts a referral to psychosocial services [8-10]. Many patients who have high distress-screening scores refuse psychosocial support, whereas some patients with lower distress levels seek out support [10-12].

If clinicians are to understand the patient's needs and encourage highly distressed patients to accept potentially helpful psychosocial services, clinicians and patients must effectively communicate [5, 13]. Successful patient–clinician communication can reduce anxiety and depression in cancer patients [14, 15], improve their satisfaction with care [16], change their beliefs and raise adherence to cancer treatments [17], and encourage patients to seek additional support [18]. However, there is evidence of alarming levels of lack of recall of relevant medical information among patients during oncological consultations [19, 20]. Intensity of emotions, cognitive complexity, and ambiguity may all cause misunderstanding during communication between patient and clinician, that may influence access to and acceptance of psychosocial support [13].

We know of no study that has assessed differences between patients' and clinicians' recall of conversations about psychosocial distress and psycho-oncological support after distress screening during the first consultation of routine oncology practice.

Our study had two aims: 1) to study the approaches by which oncologists used the Distress Thermometer (DT) to assess psychosocial distress, communicate about psychosocial distress and support options, and refer patients to psychosocial services, and 2) to compare patients' and oncologists' recall of their perceptions of the conversation.

PATIENTS AND METHODS

We conducted a prospective, observational study in the Oncology Outpatient Clinic of the University Hospital Basel in Switzerland. The methods are outlined below and are described in more detail in the study protocol [21].

Participants

All cancer patients who presented for the first time at the Medical Oncology Outpatient Clinic at the University Hospital Basel (Switzerland) were pre-screened for eligibility and interest to join the study by their attending oncologist ("Are you interested to participate in a psycho-oncological study assessing reasons for accepting psycho-oncological support?"). To be included, patients needed to be 18 years or older, fluent in German, physically and cognitively well enough to participate, and to have planned at least one additional consultation.

Standard Screening Procedure

Cancer patients are routinely screened at their first outpatient consultation for psychosocial distress, based on a stepped–care model [3]. Patients receive the DT in the waiting room. The back side of the DT describes the available in-house psycho-oncology service. Oncologists are instructed to address psychosocial distress and to provide information about the psycho-oncology service to all patients in the first consultation. They are advised to recommend the service to patients who have a clinically relevant level of distress (DT≥5), or based on their clinical judgment, or the patient's wish. Oncologists were trained in how to communicate about psychosocial distress and how to follow guidelines for referral to the psycho-oncology service.

Study Procedure

After pre-screening by attending oncologists, the study team informed eligible and interested patients about the study details and procedure. Subsequent to receiving informed consent, participants were interviewed by a member of the study team on

average 15 days (range 0–46 days) after the first consultation. Patient preference determined whether interviews were conducted via telephone (44%) or face-to-face (56%). An interview manual was used in all cases. Oncologists separately completed a paper-pencil questionnaire. This study complied with the Declaration of Helsinki. The local ethics committee approved the study (Ethikkommission Nordwest- und Zentralschweiz, Ref.Nr.: EK220/13).

Measures

Characteristics of patients and oncologists. We recorded patients' sociodemographic data in an interview and collected clinical data from their medical records. Oncologists reported their personal data in a questionnaire.

Psychosocial distress screening. To screen for self-reported psychosocial distress, we used the German version of the DT with the problem list [22]. The one-item DT (“How much distress have you been experiencing in the past week including today?”; scale from 0 "no distress" to 10 "extreme distress") has a cutoff value of 5 for clinically significant levels of distress. The problem list has five problem categories and 36 items to identify potential causes of distress. Baseline distress levels were assessed during the interview with the same question “How much distress have you been experiencing in the past week including today?” (scale from 0 "no distress" to 10 "extreme distress").

How oncologists used the DT. Oncologists were asked: "How helpful was the DT in the consultation with the patient?" (scale from 0 "not helpful at all" to 10 "very helpful"). They could choose among six reasons for using the DT (multiple answers possible): The DT was helpful 1) to assess the patient's distress; 2) to assess the patient's problems; 3) to initiate the conversation about psychosocial distress; 4) to structure the conversation about psychosocial distress; 5) for referral to the psycho-oncology service; and 6) for referral to social or pastoral care.

How oncologists and patients perceived the conversation. Oncologists and patients were asked four questions to assess communication about psychosocial distress and the psycho-

oncology service (Table 1). Oncologists' reasons for not talking about psychosocial distress and for not recommending the psycho-oncology service were recorded in open-ended questions. Patients were also asked: "How important was it for you to talk about your psychosocial distress with the oncologist?" (scale from 0 "not important at all" to 10 "very important").

Data Analysis

We assessed patients' and oncologists' recall of the conversation as cross-tabulation of all paired observations. We used multivariate logistic regression analysis to predict patients' failure to recall 'talking about psychosocial distress' (recall (yes)=0; failure to recall (no/ don't remember)=1). The oncologist was used as a random coefficient to account for potential within–oncologist clustering. We used robust standard errors to compute *P*-values and 95% confidence intervals. Predictor variables were patients' age (10-years increase), patients' distress level at the first consultation, the importance patients attach to talking about psychosocial distress with the oncologist, and time between first consultation and study interview (1-week increase). Missing data of patients' screening distress level (n=46) were imputed with patients' baseline distress levels. Missing data of patients' importance of talking (n=43) were imputed using multiple imputation method. Significance level was set at $P \leq .05$. Results were calculated with SPSS version 22 (IBM, Armonk/NY, 2013).

RESULTS

Between October 2013 and January 2016, 1,261 patients newly registered at the clinic, of whom 21 patients had no malignant tumor. Patients were excluded from the study due to insufficient German (n=164), insufficient performance status or cognitive status (n=125), or no further consultation (n=195). Oncologists did not inform 99 patients about the study due to lack of time (n=8), neglect (n=11), difficult consultation (n=59) or other reasons (n=21). Of the remaining 657 eligible cancer patients, 209 declined to participate in a

psycho-oncological study and 15 patients could not be reached. The study team approached and completely informed 433 patients about the study course, of whom 37 patients declined to participate, 38 were too highly distressed, 19 gave other reasons, and 6 could not be analyzed due to too many missing data. In total, 333 patients (77% of all approached patients) completed the study.

Sociodemographic and Clinical Characteristics

Psychosocial distress was normally distributed among participants; 53.5% of participants showed clinically significant psychosocial distress (DT≥5; Table 2).

Twenty-five oncologists participated in the study (professional seniority 0–30 years): 13 men and 12 women; mean age 36.6 years (range 28–58 years); nine senior oncologists (professional seniority ≥6 years); six oncologists in training (professional seniority ≤4 years); and ten resident oncologists (professional seniority ≤2 years).

How Oncologists Used the DT

In 65.5% of all evaluable consultations (*n*=278), oncologists rated the DT as helpful or neutral (values 5–10). Answers from 55 consultations were missing (problems with DT delivery by clinical staff, *n*=18; not being provided by patients, *n*=22; missing answers from oncologists, *n*=6; lost documents, *n*=9). Oncologists evaluated DT usefulness for 207 consultations and gave three main reasons: The DT helped initiate the conversation about psychosocial distress (58.0%); it helped assess the patient's distress (45.9%); and it helped suggest a referral to the psycho-oncology service (25.1%). Other answers were given in fewer than 17% of consultations.

How Oncologists and Patients Perceive the Conversation

Oncologists reported talking with their patients about psychosocial distress in 96.6% of consultations (Figure 1); 53.8% of the patients remembered the conversation (patient-oncologist agreement 51.8%; Table 3). The only reason oncologists gave for not broaching the subject was lack of time. Oncologists informed 97.5% of all patients about the existence of psycho-oncology service, and 84.1% of the patients affirmed (patient-

oncologist agreement 82.2%). Oncologists provided detailed information about the benefit of psycho-oncological support to 89.9%; 18.2% of the patients remembered detailed information (patient-oncologist agreement 16.6%). Oncologists recommended 56.6% of all patients across all distress levels to make use of the psycho-oncology service (73.8% of patients with high distress [DT≥5]; 38.9% of patients with low distress [DT<5]; Figure 2), and 23.7% of all patients remembered (patient-oncologist agreement 17.5%). The reasons oncologists gave for not recommending the service to patients with high distress were (in order of frequency): “The patient… 'receives sufficient social support', 'already receives psychological/psychiatric support', 'distress level seems lower than indicated on the DT', 'shows no perceivable need for support', 'declines psycho-oncological support for now/ in general', 'has a curative treatment approach'.”

Predictors of Patients' Failure to Recall Talking about Psychosocial Distress

Patients failed to remember the discussion about psychosocial distress with the oncologist in 46.2% (*n*=154) of cases. Predictors of patients' failure to recall were higher age (odds ratio [OR]=1.36; 95% confidence interval [CI], 1.13-1.64; *P* = .001), higher psychosocial distress (OR=1.12; 95% CI, 1.02-1.23; *P* = .021), and attaching less importance to talking about psychosocial distress with the oncologist (OR=0.83; 95% CI, 0.76-0.89; *P* < .001). Time between the first consultation and recall in the interview did not predict patients' failure to recall (OR=1.13; 95% CI, 0.95-1.34; *P* = .175).

DISCUSSION

In our investigation, oncologists indicated that they had used distress screening more to initiate the conversation about psychosocial distress than for actual screening purposes and that they had addressed the subject of psychosocial distress in almost all initial outpatient consultations. Patients, on the other hand, failed to recall much of the information oncologists reported to have shared.

In two-thirds of all consultations, oncologists in our study considered the DT helpful for clinical practice. Why in the other third of consultations oncologists did not perceive

the DT as helpful remains unclear. Nevertheless, oncologists in our study reported that they had addressed psychosocial distress in almost all initial consultations and provided information about the in-house psycho-oncology service, as well as details of psycho-oncological support. Contrary to current guidelines [3], oncologists in our study did not recommend the psycho-oncology service to all highly distressed patients; additionally they did recommend the service to some patients with low distress scores. For oncologists, factors other than the level of distress on the DT (e.g. the patient was already receiving sufficient social support) may have influenced their decision of whom to give or withhold a recommendation.

Half of all cancer patients did not remember psychosocial distress being discussed at all. Predictors of patients' failure to recall having talked about psychosocial distress were higher age, higher distress level at first consultation, and attaching less importance to talking about psychosocial distress with the oncologist. In addition, only one fourth of all patients recalled that the oncologist had provided a recommendation, and only a fifth remembered details of the benefits of psycho-oncological support having been provided by the attending oncologist. However, most patients did recall the information about the in-house psycho-oncology service. Since this information was relatively simple and was given both orally by the oncologist and in written form on the back side of the DT, it is possible that combining written and oral information may make it easier for patients to remember.

Research on communication in cancer care has shown that patients miss a remarkable amount of the information presented to them by their clinicians [19]. The stress that accompanies bad news may cause the patient’s attention to narrow focus to the information they find most pressing [23]. Additionally, the importance patients attach to addressing psychosocial distress depends on contextual factors like the treatment trajectory and goal [24]. Also, Jansen et al. [25] found that recall of information significantly decreases with age. Patients and oncologists may, furthermore, have different understandings and different expectations when discussing distress [26, 27], and may vary in perceptions

regarding recommendations and explanations of psychosocial support. Oncologists may underestimate the complexity of the detailed information they deliver, and overestimate the capacity of a patient to remember it [28].

Our results, like those of others [2, 29, 30], emphasize that distress-screening tools create an opportunity for clinicians to initiate the communication about psychosocial distress with cancer patients. According to Epstein and Street [13] an effective patient–clinician communication is reached by aligning patients' and clinicians' perspectives by making needs, goals, and expectations explicit early in the clinical encounter. This requires cooperation, knowledge, and skills from clinicians, making a communication training crucial [13, 31].

Our study has several strengths and limitations. Although our results represent real-life oncology practice, it is a single-center study conducted in one major Swiss university medical center. Single-center studies are common in the medical literature [19, 32, 33] and may provide valuable heuristic information. However, they may not prove representative of the majority of institutional settings, are likely to reflect national and cultural variations, and therefore require international multicenter replication. Furthermore, due to the particulars of our recruitment process, oncologists did not inform 13% of all eligible patients about the study, and in the pre-screening 30% of all eligible patients declined further information about the purpose and course of the study. Therefore, 43% of all eligible patients were not approached for study participation. This procedure may have caused a selection bias. However, 77% of all approached patients completed the study.

Regarding strengths, our investigation is, in fact, one of few psychological studies that has recruited patients in the period of increased vulnerability awaiting cancer treatment [3] and is the first study focusing on the content of patient–clinician communication during a standard distress-screening procedure. Because of the original character of our results, it should be interpreted carefully, and replication is necessary.

Another strength is that the study incorporates subjective perspectives of both patients and oncologists. However, because we did not record patient–oncologist consultations because we did not want to disrupt the first consultation, we only know what oncologists and cancer patients reported. Here again, because adherence to standard screening procedures can differ across clinics [34, 35], our results may not be generalizable to other settings.

For an improved psychosocial care in oncology, the clinical distress screening pathway may require some rethinking [7, 36]. The acceptability of psychosocial care depends very much on the communication between patients and clinicians [31]. Therefore, distress-screening programs must consider new approaches to enhance patient-clinician communication 1) by training oncologists to effectively communicate about psychosocial distress and psychosocial health needs, 2) by promoting greater cognizance of the various individual and contextual factors that can influence information processing among patients (e.g. older age, high initial distress), and 3) by repeating the conversation about psychosocial distress and support options at different phases of oncological treatment and with different modes (e.g. combine oral and written information). Overall, the clinical distress screening pathway might benefit from detailed recommendations to guide clinician interaction and communication with the patient.

To conclude, we examined patient–clinician communication during a standard distress screening procedure. From the oncologist's perspective, the distress screening helped them recognize and initiate communication about psychosocial distress. However, we found that patients failed to recall much of the information oncologists reported to have shared.

ACKNOWLEDGMENTS

This study was supported by the Swiss Cancer League (Berne, Switzerland, Grant No. KLS-3186-02-2013). We thank all patients who shared their insight into their experiences, and all oncologists for their time and commitment to our study. We also thank our research

team and colleagues for assisting with data collection. A special thank goes to Claudia Steiner for editing this manuscript. We also acknowledge Kali Tal's editorial contributions (i.e., grammatical assistance, stylistic suggestions to draft). Editing was funded by a personal grant for Diana Zwahlen from the University of Basel.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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TABLES

Table 1. Oncologists' and Patients' Perception of their Conversation.

Variables	Oncologists' Questionnaire	Patients' Interview Questions
Talking about Psychosocial Distress	Q: "Did you talk with the patient about his/her psychosocial distress?"	Q: "Did the oncologist talk about your psychosocial distress with you?"
	A: Yes/ No	A: Yes/ No/ Don't remember
Information about the Psycho-Oncology Service	Q: "Did you inform the patient about the psycho-oncology service?"	Q: "Did the oncologist inform you about the psycho-oncology service?"
	A: Yes/ No	A: Yes/ No/ Don't remember
Detailed Information about Psycho-Oncological Support	Q: "Did you inform the patient about how the psycho-oncologist can provide support?"	Q: "Did the oncologist inform you about how the psycho-oncologist can provide support?"
	A: Yes/ No	A: Yes/ No/ Don't remember
Recommendation to Attend the Psycho-Oncology Service	Q: "Did you recommend that the patient attends the psycho-oncology service?"	Q: "Did the oncologist recommend that you attend the psycho-oncology service?"
	A: Yes/ No	A: Yes/ No/ Don't remember

Q, question; A, answer format.

Table 2. Participants' Sociodemographic and Clinical Characteristics (*n*=333, unless otherwise stated)

	n	%
Age, in years		
Mean (SD)	60.5 (14.0)	
Range	19-93	
Sex		
Female	151	45.3
Male	182	54.7
Education		
Low (9th grade or less)	31	9.3
Middle (apprenticeship/ high school)	186	55.9
High (diploma/ university degree)	166	34.8
Living with a partner		
Yes	233	70.0
No	100	30.0
Living with children		
Yes	72	21.6
No	261	78.4
Distress Thermometer*		
DT score 0-4	132	46.5
DT score 5-10	152	53.5
Mean (SD)	4.7 (2.7)	
Cancer type°		
Breast cancer	67	20.1
Thoracic malignancies	59	17.7
Hematologic malignancies	51	15.3
Genitourinary cancer	28	8.4
Melanoma/ skin cancer	27	8.1
Gastrointestinal (non-colorectal) cancer	22	6.6
Central nervous system tumors	16	4.8
Colorectal cancer	15	4.5
Head and neck cancer	14	4.2
Sarcoma	13	3.9
Gynecologic cancer	5	1.5
Others	17	5.1
Time after initial cancer diagnosis, in weeks		
Median (range)	4 (0-264)	
Current oncological treatments (multiple treatments possible)		
Systemic treatment§	8	89.5
Radiotherapy	109	32.7
Surgery	34	10.2
No treatment/ watch and wait/ others	21	6.3
Oncological treatment intent		
Palliative	128	38.4
Curative	205	61.6
Tumor staging		
Local	92	27.6
Locally advanced	84	25.2
Metastatic	105	31.5
Other	52	15.6
ECOG		
0-1	291	87.4
≥ 2	42	12.6

Abbreviations. SD, standard deviation; DT, Distress Thermometer; ECOG, index of performance status (lower values indicating better performance status)

*n=284, DT information from 49 patients were missing due to non-delivery of the DT by clinical staff (n=18), not being provided by patients (n=22), and lost documents (n=9)

°n=334, one participant with two cancer types

§Systemic treatment includes chemotherapy, immunotherapy, hormone therapy, and targeted therapy

Table 3. Oncologists' and Patients' Recall of their Conversation§.

Talking about Psychosocial Distress* (n=326)				**Detailed Information** about the Psycho-Oncology Service* (n=313)			
		Oncologist				Oncologist	
		Yes	No			Yes	No
Patient	Yes	169 (51.8%)	5 (1.5%)	Patient	Yes	52 (16.6%)	4 (1.3%)
	No	108 (33.1%)	6 (1.8%)		No	152 (48.6%)	14 (4.5%)
Information about the Psycho-Oncology Service* (n=326)				**Recommendation** to Attend the Psycho-Oncology Service* (n=302)			
		Oncologist				Oncologist	
		Yes	No			Yes	No
Patient	Yes	268 (82.2%)	7 (2.1%)	Patient	Yes	53 (17.5%)	20 (6.6%)
	No	21 (6.4%)	1 (0.3%)		No	94 (31.1%)	96 (31.8%)

Note. *Patient does not remember: Talking (n=38, 11.7%); Information (n=29, 8.9%); Detailed Information (n=91, 29.1%); Recommendation (n=39, 12.9%) §Questions are listed in Table 1.

FIGURES

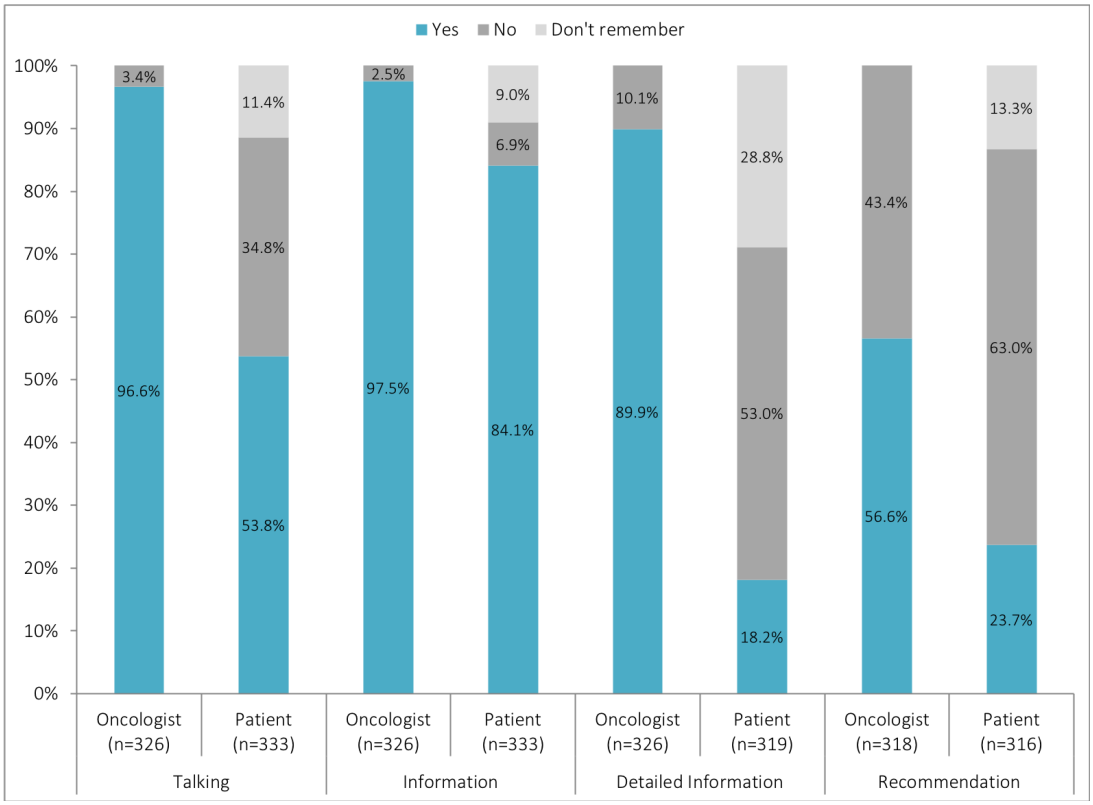

Fig. 1 Descriptive diagram of oncologists' perception and patients' perception of their conversation in the first ambulatory consultation on four variables (questions are listed in Table 1). Oncologists' and patients' data are separated from each other, each column representing oncologists or patients' view. *Blue* indicates oncologists or patients recall that they have talked about this issue. *Dark grey* indicates oncologists or patients recall that they have not talked about this issue. *Light grey* indicates patients don't remember if they have talked about this. Number of consultations (*n*) varies because of missing data

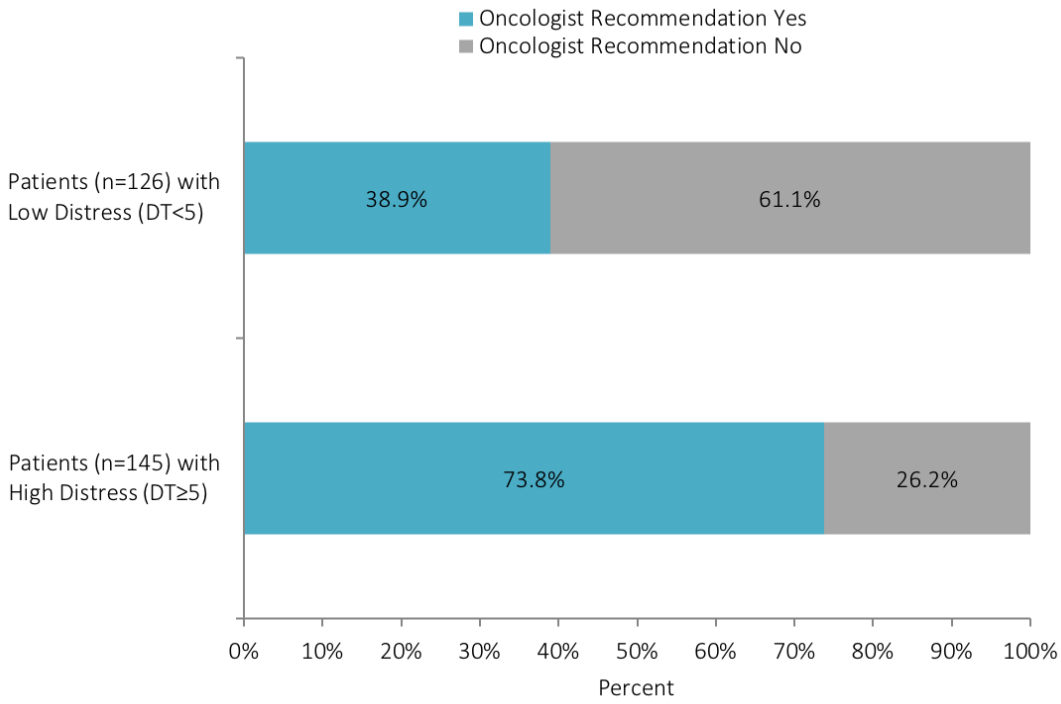

Fig. 2 Percentage of recommendations from oncologists to attend the psycho-oncology service (*blue*: oncologist gave a recommendation; *grey*: oncologist gave no recommendation) to patients with low psychosocial distress (DT<5, *n*=126) and high psychosocial distress (DT≥5, *n*=145)

Abbreviations. DT, Distress Thermometer

5 Discussion

5.1 Summary of findings

To understand the health care needs of cancer patients, we conducted a longitudinal, observational mixed-methods study with prospective data to assess distress, intention, and uptake of the psycho-oncology service. From the patient's perspective, severity of psychosocial distress was one (but not the only) determinant of patients' intention to accept psycho-oncological support. Other factors that shaped cancer patients' intentions included attitude to psychological support, coping strategies, and perceived social and professional support. We found that one-third of all cancer patients were ambivalent about using the psycho-oncology service. These patients also reported high distress values on the DT and were generally open to psychological support. However, a majority of ambivalent patients did not attend the outpatient psycho-oncology service over a period of four months. In total, a quarter of all participating patients attended the psycho-oncology service over a four-month period. Factors predicting actual uptake included younger age, higher education, and higher distress levels. However, the strongest predictor of uptake was oncologists' recommendation to attend the psycho-oncology service.

From the oncologist's perspective, DT was found to be helpful in two-thirds of all consultations, using the screening tool principally to open the door to a conversation about psychosocial issues. In almost all cases, the oncologists addressed the issue of psychosocial distress and provided information about the outpatient psycho-oncology service. However, patients often failed to recall this conversation. Higher age, higher initial distress, and attaching less importance to talk about distress with the oncologist predicted patients' failure to remember.

5.2 Discussion and integration

Cancer is a potentially life-threatening disease attended by adverse effects on physical and psychological well-being. Many cancer patients who might benefit from psychosocial support fail to attend these services. The study aimed to understand the health care needs of cancer patients (cf. Figure 2) and to reduce any barriers to referral to supportive care services.

For uptake of psychosocial care, *information* about supportive care services is a prerequisite, and lack of information is therefore a barrier (Dilworth et al., 2014; Mosher et al., 2014; Neumann et al., 2010). As in other outpatient oncological settings that use a stepped model of psycho-oncological care (Singer et al., 2017), all participating patients in our study were supplied with written information about the outpatient psycho-oncology service (on the reverse side of the DT; see Appendix B) prior to their first outpatient oncological consultation. The participating oncologists were asked to inform all patients about the outpatient psycho-oncology service in the first consultation. In fact, 84% of all patients recalled this information, which was relatively simple and was provided both orally and in written form. These features seem essential if patients in highly stressful situations are to remember the information provided (Finset, 2015; Kessels, 2003; Langewitz et al., 2015).

More than half of all patients reported a *normative need* for support (i.e., high distress values of DT≥5). In our study, psychosocial distress levels were slightly higher than those reported in other studies (Carlson et al., 2010; Zabora et al., 2001), which might be explained by the time of data collection. Using the DT, we routinely screened all patients for psychosocial distress shortly before the first consultation with the oncologist, when patients receive information about their cancer and treatment options, evoking existential fear and stress. In most other studies, distress was assessed at home or at various times at the clinic but rarely prior to the first consultation (Admiraal et al., 2016; Faller, Weis, et al., 2016).

In our study, 25% of all patients *expressed a need* to access the psycho-oncology service (intention *yes*); 42% expressed no need (intention *no*); and 33% were ambivalent (intention *maybe*). Combining *normative* and *expressed needs*, 67% of highly distressed patients (DT≥5) did not want to make immediate use of the psycho-oncology service (35% *no*; 32% *maybe*). At the same time, 45% of low distressed cancer patients (DT<5) were open to psycho-oncological support (15% *yes*; 30% *maybe*). These results align with many other studies reporting 42–75% of high distressed cancer patients with no need for support and 10–44% of low distressed patients with a need for support (see section 2.1.4). Our results highlight the difficulties encountered in referring patients experiencing a high level of distress to supportive care services.

The novel aspect of our study was its qualitative approach, which enabled us to identify different patterns of emerging motives for declining psycho-oncological support. By identifying these patterns, we can improve referral of patients with high distress levels to supportive care services. In line with the findings of Clover and colleagues (Clover et al., 2015), we identified three main reasons for declining support: existing social support, subjective well-being, and self-determination/ self-management. Additionally, we found negative attitudes towards psychological support. Negative attitudes may reflect a biomedical understanding of illness and a tendency to avoid help-seeking behaviour that is common in mental health care settings (Clover et al., 2015). However, the needs of these patients might be better met by approaches that focus on reducing stigmatization and enhancing self-determination.

In contrast, the needs of patients with *maybe* intention might be better addressed by taking an "if-then" approach to discussing service uptake. This group cited reasons both for psychological support (e.g. fears and uncertainties) and against it (e.g. existing social support; subjective well-being). These entailed a lot of if-then thinking (e.g. "if the treatment has side effects then I might use the service"), while remaining open to using the service at a later stage. Their distress levels were significantly raised as compared to the *no* intention group, but they were unable to decide between uptake and refusal,

confirming the tremendous uncertainty that patients experience during the first weeks following a cancer diagnosis.

Patients with an ambivalent intention may have gone unrecognized in clinical practice to date because supportive care needs are captured (if at all) only once, using a dichotomous response format (yes/no) and are not routinely repeated if, for example, a patient's health deteriorates, if social support diminishes, or if treatment causes side effects (Baker-Glenn et al., 2011). To capture all of a cancer patient's need for supportive health care, a threefold assessment (*yes/maybe/no*) is recommended. Finding the right approach to meet the needs of each individual could optimise psycho-oncological health care delivery.

Patients with a *yes* intention reported positive attitudes to psychological support, knowledge about what psychologists do and how they could help, and support-seeking concepts of coping. By implication, mental health literacy, knowledge, and patient empowerment seem important for patients' verbalization of need and may increase service uptake (Faller et al., 2017; Faller, Koch, et al., 2016; Mehnert & Koch, 2008; Neumann et al., 2010; Salander, 2010; Steginga et al., 2008). On that basis, supportive cancer care should always include detailed information about access to and benefits of psycho-oncological support.

In total, 23% of all cancer patients used the outpatient psycho-oncology service over a period of four months. Among these, 65% of high distressed patients who expressed a *yes* intention actually used the service while 7% who expressed a *no* intention and 12% who expressed a *maybe* intention used the service. It is well known that some patients who want and are offered psycho-oncological support do not attend (Brebach et al., 2016) and that needs can change over time (Baker et al., 2013; McCormick & Conley, 1995). In their qualitative study, Baker and colleagues concluded that treatment stage influences patients' readiness to address emotional needs (Baker et al., 2013).

As in previous studies, we found that patient-related characteristics like younger age and higher education level predicted psycho-oncology service uptake (Faller et al.,

2017; Faller, Weis, et al., 2016; Mehnert & Koch, 2008; Steginga et al., 2008; Zeissig, Singer, Koch, Blettner, & Arndt, 2014), as did higher distress levels (Curry, Cossich, Matthews, Beresford, & McLachlan, 2002; Faller et al., 2017; Steginga et al., 2008). In contrast to other studies, however, female gender was not associated with higher uptake (Clark et al., 2017; Ernst, Lehmann, Krauß, Köhler, & Schwarz, 2009). In general, further attempts should be made to understand the supportive care needs of older and less well-educated patients.

Interestingly, the strongest predictor of psycho-oncology service uptake was not level of distress or another patient-related characteristic. Rather, patients who reported an oncologist recommendation to attend the psycho-oncology service were six times more likely to use the service than those who did not report an oncologist recommendation. In other words, in a situation of huge uncertainty and threat, patients seem to trust oncologists' expertise and judgement, confirming that trustful patient-clinician relationships are crucial in cancer care. Our study supports recent findings (Beesley et al., 2016; Salmon & Young, 2017a, 2017b) that these trustful relationships depend on a patients' perception of clinicians' expertise and authority. Vulnerable patients are likely to form an emotional bond with a clinician to whom they attribute experience and the power to build a secure base when facing the threat of cancer (Salmon & Young, 2017b).

At the same time, patients who were unsure whether an oncologist had recommended attending the psycho-oncology service were also four times more likely to access the service than patients who did not report an oncologist recommendation. These patients either did not remember the recommendation, did not remember the source of the information (e.g. oncologist/nurse/friend/spouse; first/second consultation), or were already positively disposed to psychological support and the answer was socially desired. We found that patients' attitudes were strong indicators of their intention to use or refuse psycho-oncological support (along with coping, distress, and support). Patients' attitudes to psycho-oncological support may influence both help-seeking and attendance; they may also affect the behaviour of oncologists, who may be more likely to initiate discussions

and provide a referral if they detect more explicit and frequent signs of psychosocial concern (Sheldon, Blonquist, Hilaire, Hong, & Berry, 2014). We also found that factors other than level of distress influenced oncologists' decisions to give or withhold a recommendation, including existing social support, absence of need, negative attitude, and curative treatment intent.

Patients in our study did not recall detailed information that oncologists claimed to have shared about the psycho-oncology service. First consultations are typically full of new and potentially stressful medical information about cancer treatment and goals, and there is evidence of lack of recall of relevant medical information (Gabrijel et al., 2008; Gattellari, Voigt, Butow, & Tattersall, 2002). Retention of information is limited in situations of intense emotion, cognitive complexity, and ambiguity (Epstein & Street, 2007). Because survival is the principal goal, detailed information about the psycho-oncology service may not meet the patient's situational needs, and it may be better to share this information at a later appointment.

From an oncologist's perspective, the DT proved useful as a tool for initiating discussion about psychosocial distress and support options, creating an atmosphere of openness in which to address psychosocial issues. However, about half of the participating patients did not remember this conversation; these included older patients and those with higher initial distress levels, as well as patients who considered it less important to talk with their oncologists about psychosocial distress. Because we have no objective records of the consultations, it is difficult to conclude from the available data whether oncologists failed to communicate clearly enough or whether patients neglected or failed to recall the information. Mackenzie and colleagues found that most patients who preferred not to talk with the oncologist about their distress said that other issues were more important for them in an oncological consultation (Mackenzie et al., 2015). Additionally, oncologists and patients might have different views about what it means to talk about psychosocial distress. Nevertheless, it seems clear that oncologists who initiate the discussion of psychosocial distress may reduce the risk of unrecognized psychiatric comorbidities and

stigmatization by validating patients' needs (Faller, Weis, et al., 2016; Jones et al., 2011; Mackenzie et al., 2015; Taylor et al., 2011; Wright et al., 2004).

Given their influence, oncologists need to act sensitively and responsibly to help patients overcome any barriers to accessing psycho-oncological support. Our results highlight how distress screening tools create an opportunity for oncologists to initiate communication with their patients about distress and to recommend the psycho-oncology service to vulnerable patients. Oncologists should not become counsellors for patients, but they should be facilitators, creating an atmosphere in which cancer patients are encouraged to address their psychosocial concerns in the same way as their physical concerns, where psychological symptoms are assessed, health care needs are discussed, information is provided, and treatment options are considered.

5.3 Future directions

If oncologists are to understand patients' needs and encourage highly distressed patients to accept potentially helpful psychosocial services, oncologists and patients must communicate effectively (Epstein & Street, 2007; Institut of Medicine, 2008). In this regard, distress screening programmes can benefit from new approaches 1) by training oncologists to communicate effectively about psychosocial distress and psychosocial health care needs, taking account of the communication context (e.g. expertise and authority preferred in situations of threat); 2) by promoting greater cognizance of the various individual and contextual factors that can influence information processing among patients (e.g. older age, high distress); and 3) by reiterating the issue of psychosocial distress and options for support at different phases of the oncological treatment, using different modes of communication such as combining oral and written information.

The present findings support claims for new approaches to enhance patient-oncologist communication and invite further investigation of how effective patient-oncologist communication is achieved.

5.4 Strengths and limitations

This project has several strengths and limitations. This was a single-centre study, conducted in a comprehensive cancer centre at a major Swiss university hospital. Single-centre studies are common in the medical literature (Ellis et al., 2009; Gabrijel et al., 2008; Trevino, Fasciano, & Prigerson, 2013) and can provide valuable heuristic information. However, they may not be representative of institutional settings more generally; as they are likely to reflect national and cultural variations, international multicentre replication is required.

In the present study, the consultant oncologist recruited patients. This strategy had several advantages. As oncologists are the first and closest contact for outpatients, being invited by a physician to participate in a psycho-oncological study may serve to reduce any associated stigma. There is no additional burden for cancer patients at a time of increased vulnerability while awaiting treatment, and the clinic is a naturalistic setting. However, there is also a risk of bias if oncologists informed only patients they considered to be interested or healthier. In fact, 13% of all eligible patients were not informed about the study; 28% of eligible patients did not want any further information about the study, and 12% refused to participate after being informed. Nevertheless, our sample was large and gender-balanced and included a broad range of cancer types. The sample was representative for our clinic and was comparable to other outpatient oncological settings using a stepped-care model (Singer et al., 2017). Again, because of the originality of our recruitment strategy, the findings should be interpreted carefully, and replication will be necessary.

We decided against audio- or video-recordings of consultations because of the large number of participants and because we did not want to disrupt the first consultation. For that reason, we have no objective record of the consultations. Instead, our findings are based on patients' and oncologists' subjective reports, which we consider central to their actual behaviour. Adopting a qualitative approach, we took notes during the interviews

and subsequently wrote reflective postscripts (Mey & Mruck, 2010). We countered possible interviewer bias by relying on a detailed interviewer manual and ensuring that interviewers were closely supervised. However, social desirability and recall biases must be acknowledged as potential sources of bias (Gabrijel et al., 2008; Van De Mortel, 2008).

The present study offers a novel, in-depth qualitative analysis of patients' supportive care needs as a crucial extension of previous research. To our knowledge, it is the first study to focus on the content of patient-oncologist communication during a standard distress screening procedure in routine oncology practice. It is also the first longitudinal study of a large sample of cancer patients in the early phase of cancer treatment to monitor psycho-oncology service uptake after documenting supportive care needs.

6 Conclusion

To achieve evidence-based change in comprehensive cancer care, we examined patients' distress, intention, and uptake of psycho-oncological support, and patient-oncologist communication during a standard distress screening procedure in a longitudinal, mixed-methods prospective observational study.

Severity of distress (*normative need*) was found to be quantitatively and qualitatively associated with patients intention (*yes, maybe, no*) to access psycho-oncological support (*expressed need*). Other deciding factors included coping strategies, attitude to psychological support, and perceived social and professional support. Patients' health care needs are relevant in comprehensive cancer care because more than half of highly distressed patients do not wish to make immediate use of the psycho-oncology service. However, we found that about half had no such intention while the other half was ambivalent. Finding the right approach to meet the needs of each patient group (e.g. enhancing self-determination vs. discussing "if-then" thinking) seems likely to optimise psycho-oncological health care delivery.

Patients' actual uptake of support was predicted by higher distress levels, younger age, and higher education level, as well as by oncologist recommendation to attend the service. Oncologists play a central role in comprehensive cancer care in terms of providing information, reducing stigmatization, and recommending attendance at the psycho-oncology service. Repeated screening of distress and provision of detailed information about the psycho-oncology service during the cancer trajectory may support the goals of both patients and oncologists. For oncologists, the DT proved helpful in initiating a conversation about psychosocial distress and support services. However, older, less well-educated, and high distressed patients often failed to recall much of the information that oncologists reported sharing. Towards improving comprehensive cancer care, we suggest that oncologists should address and discuss patients' health care needs as a matter of

routine clinical practice, and distress screening programmes must consider new approaches to enhance patient-oncologist communication.

7 References

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Zwahlen, D., Tondorf, T., Rothschild, S., Koller, M. T., Rochlitz, C., & Kiss, A (2017). Understanding why cancer patients accept or turn down psycho-oncological support: a prospective observational study including patients' and clinicians' perspectives on communication about distress. *BMC Cancer, 17*, 385. https://doi.org/10.1186/s12885-017-3362-x

8 Appendices

Appendix A: Study protocol

Zwahlen *et al. BMC Cancer* (2017) 17:385
DOI 10.1186/s12885-017-3362-x

BMC Cancer

STUDY PROTOCOL Open Access

Understanding why cancer patients accept or turn down psycho-oncological support: a prospective observational study including patients' and clinicians' perspectives on communication about distress

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Abstract

Background: International standards prioritize introducing routine emotional distress screening in cancer care to accurately identify patients who most need psycho-oncological treatment, and ensure that patients can access appropriate supportive care. However, only a moderate proportion of distressed patients accepts referrals to or uses psycho-oncological support services. Predictors and barriers to psycho-oncological support service utilization are under-studied. We know little about how patients and oncologists perceive the discussions when oncologists assess psychosocial distress with a screening instrument.
We aim to 1) assess the barriers and predictors of uptake of in-house psycho-oncological support along the distress screening pathway in cancer patients treated at a University Oncology Outpatient Clinic and, 2) determine how patients and clinicians perceive communication about psychosocial distress after screening with the Distress Thermometer.

Methods: This is a quantitative prospective observational study with qualitative aspects. We will examine medical and demographic variables, cancer patient self-reports of various psychological measures, and aspects of the patient-clinician communication as variables that potentially predict uptake of psycho-oncological support service. We will also assess the patients' reasons for accepting or refusing psycho-oncological support services. We assess at three points in time, based on paper-and-pencil questionnaires and two patient interviews during the study period. We will monitor outcomes (psycho-oncology service uptake) four months after study entry.

Discussion: The study will improve our understanding of characteristics of patients who accept or refuse psycho-oncological support, and help us understand how patients' and oncologists perceive communication about psychosocial distress, and referral to a psycho-oncologist. We believe this is the first study to focus on factors that affect uptake or rejection of psycho-oncological support services along the screening and referral pathway. The study 1) combines standard assessment with qualitative data collection, 2) embraces patient and oncologist perspectives, and, 3) focuses on patient-clinician communication about psychosocial issues raised by a standard screening instrument.
Our results may improve routine practices and eliminate barriers to adequate health care, and make it easier to recognize patients with high distress levels who underuse the service.

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Background

Routine distress screening identifies patients who experts believe most need psycho-oncological care. This screening is intended to give patients access to supportive care services. Distress screening also identifies comorbidities, including depression and anxiety. The Distress Thermometer (DT) is widely used and has been validated as a reliable and valid screening tool [1–5]. Distress screening is now an international standard in comprehensive care of cancer patients [6, 7] and, in many countries, a criterion for cancer center accreditation [8, 9]. In principle, distress screening should identify cancer patients in psychosocial distress and direct them to appropriate treatment services but, in practice, it is debatable whether they can solve the challenges posed by this process [10, 11].

Studies that investigated distress screening, referral, and acceptance of professional support service found low correspondence between emotional distress and uptake. Some studies found that patients who reported a higher burden of emotional symptoms were more likely to access services than those who reported a lower burden of symptoms [12–16]. Referral rates and resource utilization still seem low, given documented high levels of distress. Various studies report that distress correlates moderately or not at all with the wish for support or acceptance of a referral [17–19]. Distress scores and expert perspectives do not appear to reflect patients' needs for psycho-oncological support. It would thus be very useful to be able to offer recommendations on managing discordance between patient preference and screening results.

In addition to the clinical screening and referral process, there are other potential predictors of psycho-oncological support service uptake than emotional distress. We have some evidence that patient characteristics are linked to psycho-oncological support uptake: being younger [15, 18, 20], being female [18, 21, 22], and being more highly educated [15, 21, 23, 24].

Gaining insight into the patient decision process for or against support uptake is difficult. Although the patient-clinician conversation is an important element in the screening and referral process [25, 26], we do not know how patients and physicians perceive communication after distress, or how their perceptions influence the referral process. Few studies investigate the subjective reasons people accept or reject psycho-oncological support services, and even fewer include qualitative components. A recent review [27] found the primary patient-reported reason for rejection is they perceive *no subjective need*. The second reason was lack of information about availability of psychological support services. Other patient explanations include a preference for self-managing symptoms, or the belief that help would be ineffective.

Our overarching aim is to assess factors along the distress screening and referral pathway, so we can map the process by which patients take decisions for or against uptake of psycho-oncological support service. In our prospective observational study, we will consider distress scores, medical and demographic variables, patient self-reports of psychological and social support measures, and aspects of the patient-clinician communication as potential predictors of uptake of psycho-oncological services. We also want to assess patient and physician perceptions of communication about psychosocial issues, spurred by a standard screening instrument. We will incorporate qualitative data and assess the reasons patients give us for accepting or refusing psycho-oncological support.

Our two principal research questions are: (1) Which factors along the screening pathway determine uptake of psycho-oncological support in ambulatory cancer patients; and, (2) When the DT stimulates conversations between patients and clinicians about psychosocial distress, how do they perceive those conversations?

Methods

Study design

This is a prospective, observational, quantitative single-center study in the Oncology Outpatient Clinic of the University Hospital Basel (Switzerland) medical center.

Study participants

Cancer patients are consecutively recruited from the Oncology Outpatient Clinic, which receives approximately 600 new cancer patients per year. Patients are eligible to participate if they meet the following inclusion criteria: older than 18 years; diagnosed with any kind of solid tumor or hematologic malignancy; first consultation at the Oncology Outpatient Clinic; and, at least one more scheduled appointment. We exclude patients with insufficient command of the German language, and patients too physically weak or cognitively incapacitated to participate (evaluated by attending oncologists). Participating clinicians are oncologists and residents from the Medical Oncology Department.

Standard screening and referral procedure

Routine distress screening and referral guidelines were implemented to conform to international guidelines [6] and are standard procedure in the Oncology Outpatient Clinic since 2012. Independent of study participation, patients are given a distress screening form (Distress Thermometer, DT) [6, 28] in the waiting area on the first visit at the Oncology Outpatient Clinic, shortly before their consultation. A nurse asks patients to fill in the questionnaire; patients then hand it to the attending oncologist. The back side of the questionnaire contains information about

available professional psycho-oncological support services at the Oncology Outpatient Clinic. The oncologist discusses the score with the patient during the first consultation, if possible. Oncologists are advised to recommend psycho-oncological support to patients with clinically relevant level of distress, indicated by a score of 5 or higher on the DT. Mehnert et al. [28] guided by the patient's DT score and their own estimation of the clinically relevant level of the patient's distress, the oncologist recommends the patient to use psycho-oncological support services and discusses a referral. The patient's wish guides the referral.

Psycho-oncological support service at the Oncology Outpatient Clinic

The psycho-oncological team at the Oncology Outpatient Clinic is thoroughly integrated into the medical oncology team; it is situated on the ward and attends daily team meetings.

Oncologists' training on distress screening and communication

Oncologists were instructed about psycho-oncological procedures in a one-hour communication training that covered 1) how to discuss distress scores with patients, and, 2) how to refer patients to the psycho-oncological support service. An expert in the field of medical communication and co-investigator of the study conducted the training (A.K.).

Study procedure

Eligible patients are informed about the study by attending oncologists at their first consultation. All patients willing to participate are approached by the study coordinator after the first or second consultation on the ward, or contacted by telephone. Participants are then fully informed about the study in a separate room or by telephone and receive an informed consent form, a baseline questionnaire, and a return envelope (T0). After they provide written informed consent, participants are contacted for a baseline interview within four weeks after they are recruited (T1). Patient preference determines if the interview will be by telephone or face-to-face at the outpatient clinic. Four months later, participants receive a follow-up questionnaire by mail with a return envelope, and are contacted for a follow-up interview (T2). Oncologists complete a structured paper-and-pencil questionnaire after every first consultation with a new, eligible patient (T0). Figure 1 provides an overview of study procedure and study measures.

Summary of study visits:

- T0 (participant screening and oncologist assessment) takes place when patients fill out the DT form at their first consultation at the oncology outpatient clinic. Patients receive the distress screening form before the first consultation, and oncologists are instructed to fill out a questionnaire afterwards.
- T1 (participant baseline assessment) is the baseline assessment, a few days to four weeks after study recruitment. This assessment includes the baseline interview (telephone or face-to-face) and a paper-and-pencil questionnaire (filled out at home).
- T2 (participant follow-up assessment and outcome monitoring) takes place four months later by follow-up interview (telephone or face-to-face) and a paper-and-pencil questionnaire (filled out at home). Outcome is monitored at T2.

Interview procedure and interviewer training

Interviews will be semi-structured and conversational. Interviewers will use prompts and reflections to encourage patients to talk, and will ask open and closed questions to elicit detail where necessary. Interviewers take notes on patients' answers to open-ended questions. We will use content analysis to analyze patient answers (see section, *Analysis of qualitative data*). To guarantee the quality of the data collection process, we developed an interviewer's manual that ensures interviews will be of equally high quality, regardless of interviewer. Interviewers will be trained and supervised by an experienced clinical psycho-oncologist (D.Z.).

Ethics and data safety

This study will be conducted in accord with Declaration of Helsinki and Good Clinical Practice guidelines. The local Ethics Committee in Basel, Switzerland (EKNZ) approved the study (reference number EK 220/13). The EKNZ is eligible to approve studies in the University Hospital of Basel. Collected data will be de-identified and stored in a study-specific electronic database system, in a separate locker. A patient-specific identification number (Patient ID) is used to encode patient data. Patient identification data and patient study data will be stored separately. The translation key that links patient identification data to patient study data will be electronically and physically separate from the study database system.

Sociodemographic data, clinical data, and oncologists' personal data

Sociodemographic data (age, gender, relationship status, living status, children, education, profession, employment status, monthly household income) is collected during the baseline interview (T1). Clinical data (cancer type, tumor staging, stage of disease, weeks since diagnosis, treatment intention, current and past treatments, past cancer diagnoses, comorbidities, ECOG scale) is retrieved from the

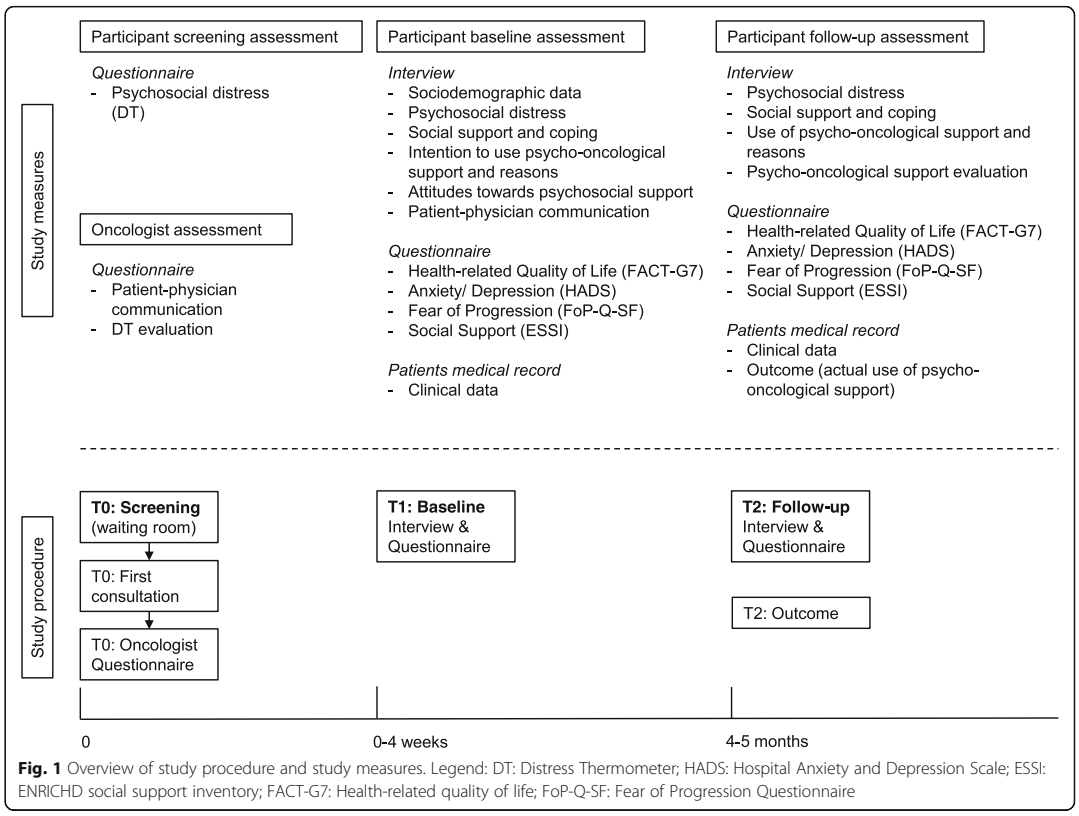

Fig. 1 Overview of study procedure and study measures. Legend: DT: Distress Thermometer; HADS: Hospital Anxiety and Depression Scale; ESSI: ENRICHD social support inventory; FACT-G7: Health-related quality of life; FoP-Q-SF: Fear of Progression Questionnaire

hospital's electronic database and from patients' medical records by an oncologist and co-author of the study (S.R.) at baseline (T1) and follow-up (T2). Oncologists' personal data (age, gender, professional experience) is gathered by a single e-mail questionnaire.

Primary outcome measure

The primary outcome is each participant's attendance (yes/no) of the in-house psycho-oncological support service (at least one appointment) during the study period. Outcome data is retrieved from patients' medical records and is ascertained by individual contact with the patient at T2.

Secondary outcome measures

Secondary outcomes include: 1) agreement of and disparities between patient and clinician perceptions of communication about psychosocial distress and referral after DT screening (Table 1); 2) patients' reasons for (non-)uptake of psycho-oncological support; 3) social support and coping measures; 4) psychosocial distress measures; and, 5) attitudes towards psycho-oncological support.

Psychosocial distress measures

Distress Thermometer (DT).

We use the German version of the NCCN Distress Thermometer with Problem List (PL) as the screening tool (T0) for self-reported psychosocial distress, and to identify the causes of expressed distress [6, 28]. The DT is well-validated as a reliable screening tool and has proven itself in clinical practice; it is short and easy to administer [1–5]. The DT contains one item: "Please circle the number [0-10] that best describes how much distress you have been experiencing in the past week including today." Patients answer on a vertical visual analogue scale from 0 ("no distress") to 10 ("extreme distress"). We use the cut-off score of 5 or greater, which Mehnert and colleagues suggest indicates a clinically significant level of distress [28]. The PL comprises five problem categories (practical problems, family problems, emotional problems, spiritual/religious concerns, physical problems), and a total of 36 potential causes of expressed distress, each of which can be answered 'yes' or 'no'.

Table 1 Patients' and oncologists' perception of the first consultation

Variables	Patients' Baseline Interview Questions (T1)	Oncologists' Questionnaire Items (T0)
Talking about psychosocial distress	Q: "Did the oncologist talk about your psychosocial distress with you?"	Q: "Did you talk with the patient about his/her psychosocial distress?"
	A: Yes/ No/ Don't remember	A: Yes/ No
Importance of talking about psychosocial distress	Q: "How important was it for you to talk about your psychosocial distress with the oncologist?"	Q: "How important was it for the patient to talk about his/her psychosocial distress?"
	A: Scale from 0 "not important at all" to 10 "very important"	A: scale from 0 "not important at all" to 10 "very important"
Information about psycho-oncological support	Q: "Did the oncologist inform you about the psycho-oncological support service?"	Q: "Did you inform the patient about the psycho-oncological support service?"
	A: Yes/ No/ Don't remember	A: Yes/ No
Specification of psycho-oncological support	Q: "Did the oncologist inform you about how the psycho-oncologist can provide support?"	Q: "Did you inform the patient about how the psycho-oncologist can provide support?"
	A: Yes/ No/ Don't remember	A: Yes/ No
Recommendation of psycho-oncological support	Q: "Did the oncologist recommend that you attend the psycho-oncological support service?"	Q: "Did you recommend that the patient attends the psycho-oncological support service?"
	A: Yes/ No/ Don't remember	A: Yes/ No
Helpfulness of psycho-oncological support	Q: "How helpful do you think psycho-oncological support would be for yourself?"	Q: "How helpful do you think psycho-oncological support would be for the patient?"
	A: scale from 0 "not helpful at all" to 10 "very helpful	A: scale from 0 "not helpful at all" to 10 "very helpful
Perceived level of psychosocial distress°	Q: "How much distress have you been experiencing in the past week including today?"	Q: "How do you perceive the level of distress of the patient?"
	A: Scale from 0 "no distress" to 10 "extreme distress"	A: scale from 0 "no distress" to 10 "extreme distress"
Content of psychosocial distress°	Q: "What are your greatest burdens?"	Q: "What are the patient's greatest burdens?"
	A: open answer field	A: open answer field
Trust in oncologist	Q: "How comfortable do you feel talking to the oncologist about personal issues?"	-
	A: scale from 0 "not at all" to 10 "very much"	-

Q Question/Item, *A* Answer format. °Questions repeated in patients' follow-up interview (T2)

Hospital Anxiety and Depression Scale (HADS)

The HADS is a 14-item self-administered questionnaire widely used to detect anxiety and depression in physically ill patients, including cancer patients, and is validated for the German language [29]. The questionnaire has two subscales (anxiety and depression) of seven items each, and a total score for each subscale (values from 0 to 21). Subscale scores between 0 and 7 indicate normal anxiety and depression levels, scores between 8 and 10 indicate borderline levels of anxiety and depression, and scores between 11 and 21 indicate clinical levels of anxiety or depression [30]. The questionnaire is administered to participants at baseline (T1) and follow-up (T2).

Fear of Progression Questionnaire (FoP-Q-SF)

The Fear of Progression Questionnaire short form (FoP-Q-SF) is a 12-item self-report questionnaire used to assess the fear of disease progression in physically ill patients [31]. The German version of the FoP-Q-SF is validated in cancer patients and is a reliable instrument, and a total sum score (higher values indicate higher levels of fear of progression) without a standardized cutoff score for clinically relevant level of fear of progression [32, 33]. The questionnaire is administered to participants at baseline (T1) and follow-up (T2).

Health-related quality of life (FACT-G7)

The German 7-item version of the Functional Assessment of Cancer Therapy - General (FACT-G) was chosen to assess health-related quality of life in cancer patients at baseline (T1) and follow-up (T2) [34]. The scale comprises three physical well-being items (fatigue, pain, nausea), one emotional well-being item (worry about condition worsening), and three functional well-being items (enjoyment of life, satisfaction with life, sleep). The recall period is the past seven days, and answers range from 0 ("not at all") to 4 ("very much") on a 5-point Likert-type scale. The total is the sum of all scores; higher values reflect higher health-related quality of life.

Social support and coping measures

ENRICHD social support inventory (ESSI).

The ESSI is a reliable and valid 5-item self-report measurement of perceived social support in physically ill patients [35]. We use the German version of the ESSI, which has good psychometric properties [36]. Answers are given on a 5-point Likertscale from 1 ("never") to 5 ("always"). Scores are summed (range 5–25) and higher scores indicate higher levels of perceived social support. Scores are dichotomized into high and low social support. Low social support is defined as a score of 18 or less, with at least two items that score 3 or less [36]. The questionnaire is administered to participants at baseline (T1) and follow-up (T2).

Other support services

Participants are asked if they attend psychosocial support services outside of the University Hospital Basel (assessed at T1 and T2; including psychiatric, psychological, or psycho-oncological support, social service, pastoral care, alternative medicine, complementary medicine).

Coping measures

Several questions elicit details on a patient's subjective perception of how they are coping with cancer, including: perceived threat ("How threatening is the illness to you right now?", scale from 0 "not threatening at all" to 10 "very threatening"); self-evaluation of coping ("How well are you dealing with your illness at the moment?", scale from 0 "not good at all" to 10 "very good"); resources for coping (open question: "Who or what has helped you so far in dealing with your illness?"); and, need to talk with someone ("Do you perceive a need to talk with someone about your illness?", from which patients can select either with friends/family, with a professional person, with both, or with no one).

Patient-physician communication

Table 1 gives an overview of variables that shape the perception of the first consultation, from the patient and oncologist perspectives.

Patients' perception of the conversation with the oncologist

Several questions in the baseline interview address the patient's perception of the conversation about psychosocial issues and psycho-oncological support with the oncologist during their first consultation (T1; details see Table 1).

Oncologists' perception of the conversation with the patient and evaluation of distress screening

Oncologists are asked to evaluate, on a paper-and-pencil questionnaire, their view of the conversation about psychosocial issues and psycho-oncological support options based on the DT in the first consultation (T0; details see Table 1). Reasons for not talking about psychosocial distress with the patient and reasons for not recommending psycho-oncological support are assessed in open answer fields. Oncologists are also asked to assess the usefulness of the DT ("How helpful was the DT in the consultation with the patient?"), rated on a scale from 0 ("not helpful at all") to 10 ("very helpful"). If the oncologist found the DT helpful, they are asked to specify why, with a choice of six pre-formulated answers (multiple responses possible):

1. "The DT was helpful to assess the patient's distress."
2. "The DT was helpful to assess the patient's problems."
3. "The DT was helpful to initiate the conversation about psychosocial distress."
4. "The DT was helpful to structure the conversation about psychosocial distress."
5. "The DT was helpful for referral to psycho-oncological support service."
6. "The DT was helpful for referral to social care or pastoral care."

Open ended questions to assess attitude and reasons for or against uptake

Patients' attitudes towards psycho-oncological support.

At baseline, attitude towards psycho-oncological support for cancer patients in general is assessed (T1) on a scale from 0 ("not meaningful at all") to 10 ("very meaningful"). Patients are also asked what expectations and fears they have about psycho-oncological support (open-ended question), if they have ever used psychological support services (yes, no), and how they evaluate their experience, from 0 ("not helpful at all") to 10 ("very helpful").

Participants' intention and reasons for (non-) uptake of psycho-oncological support

At baseline (T1), we assess participants' prospective intention to use psycho-oncological support services ("Do you intend to uptake the in-house psycho-oncological support service in the next months?" answer options: yes, maybe, no), and their reasons (in an open-ended question: "What are the reasons why you do [not/may] intend to use the in-house psycho-oncological support service?"). At follow-up (T2), we use an open-ended question to assess patients' retrospective reasons for using or refusing psycho-oncological support services in

the last four months ("What are the reasons why you did/ did not use the in-house psycho-oncological support service in the last months?"). We analyze the content of responses to open-ended questions (see below).

Statistical methods

Sample size estimation

We estimate recruitment period will last 26 months based, since about 600 new patients attend the oncology outpatient clinics per year. We plan to enroll 700 patients during this period, expect an attendance rate of 20% for the psycho-oncological support service, and a dropout rate of no more than 25%. We estimate that 140 of our study patients will have an outcome, which gives us the power to spend around 9 to 14 degrees of freedom (10–15 events per degree of freedom) in the final regression model and to avoid overfitting the model.

Statistical analysis

This project allows us to address questions related to the uptake or non-uptake of psycho-oncological services. We are primarily interested in individual patient factors, and physician-related factors that explain and predict uptake of psycho-oncological services. Statistical methods are thus specified separately for each research question. To describe the population characteristics of enrolled patients, we will display the frequency distributions for categorical data and means or medians for continuous data.

The primary outcome and aim of the project are patient and physician factors of psycho-oncological service uptake. The primary outcome of service uptake or non-uptake is defined and ascertained as a binary variable, which we will analyze with logistic regression analysis. To develop explanatory models for the primary outcome, we will first consider expert knowledge to define candidate predictors and potential interactions. We will also explore alternative candidate selection techniques as described by Harrell [37] and Steyerberg [38], and compare the properties of the different models. For continuous predictors (patient age, DT measurement, etc.), we will check the linearity assumption with restricted cubic spline transformations [37, 38]. To deal with potential missing covariate values, we will use multiple imputation and compare the complete case analyses.

Analyses that focus on oncologist perceptions of patients' distress and their need for psycho-oncological service referral will cluster within physicians. In these situations, we may use robust estimation or random-effects modeling to account for clustering. We may use intra-class correlation to assess variance components between physicians for numeric data and contingency table analyses, or hierarchical modelling to assess paired patient-physician consultation data with binary response variables.

If there was a follow up assessment, the data of that assessment will be entered for analyses. We will use descriptive methods to summarize the frequency (categorical variables) or the distribution of continuous (means [SD] or median [IQR]) baseline variables and the frequency distribution of the dependent variable. We will also run and report comprehensive analyses of missing data and drop out. We will use logistic regression analysis to test the impact of the predictor variables (see, "objectives and research question") on the outcome use or non-use of psycho-oncologic support.

We will assess univariate associations in logistic regression analysis. We will select relevant predictor variables for multivariable models using univariate preselection, based on a liberal p-value of $p < 0.2$ [37, 38]. Other than adjusting for age and gender, we will retain significant predictors in the multivariable model based on a type-1 error rate of 5%. For continuous predictors, we will also study non-linear associations using restricted cubic spline transformations with 3–5 knots [37, 38]. Independent variables that arise from patient-physician communication will be "nested within physicians". We will thus consider using multilevel modeling to account for within physician correlation. If within patient correlation (intra-class correlation) is low (e.g. < 0.05), this will indicate that the variance components between physicians are low. In this situation, regression models for the total patient sample will reveal unbiased SEs. To check agreement between patient and physician perceptions, depending on the nature of the measurement, we will use contingency table analyses or compute the intra-class correlation.

Analysis of qualitative data

Interviewers will be trained to note key messages of patients' answers to open-ended questions. Patients' answers will be recorded in first person. We will use Content Analysis to analyze responses to open-ended questions [39], in MAXQDA 12 (VERBI Software, Germany), a qualitative data analysis software program. A team of trained researchers will discuss the responses to guarantee high quality content analysis. Cohen's kappa statistics (κ) will be used to assess inter-rater reliability between independent raters.

Discussion

Many patients with high distress levels do not want psycho-oncological support [40]. This prospective observational study will help us identify predictors and barriers to psycho-oncological support service uptake along the distress screening pathway. We will learn what patients and oncologists think of their communication about psychosocial distress, based on results from a distress screening tool.

We believe this is the first study to consider factors along the distress screening and referral pathway to map the decision process of patients. We 1) combine standard assessment with qualitative data collection, 2) embrace patient and oncologist perspectives, and, 3) focus on communication-related aspects of the distress screening procedure.

Clinical practice and research show that severity of distress is not the only deciding factor in whether a patient accepts a referral to psychosocial services. The presence of clinically relevant levels of psychological distress does not necessarily translate into a patient's desire for referral for treatment, but patients with negative screens may ask for psycho-oncological services, e.g. [17–19].

Patient characteristics linked to support service uptake

Research has linked older age [15, 18, 20] and lower education [15, 21, 23, 24] to less service use, even when older and less-educated patients have higher levels of distress, pain, and fatigue. Some studies report that women [18, 21, 22] are more likely to be referred to psycho-social services. But Waller [15] found that very fatigued women were less likely to access services than very fatigued men. Other contextual factors, including treatment modalities, were associated in different ways with patients' desire for psychological support. Evidence on additional patient characteristics and clinical aspects associated with acceptance of psycho-oncological support other than distress is rare, and participants and study designs were heterogeneous.

Patient-physician conversation based on results from a distress screening tool

Communication about psychosocial issues is delicate. There is evidence that clinicians do not systematically inquire into the emotional problems of patients, and many clinicians prefer patients to bring up a problem. On the other hand, patients are reluctant to disclose problems [41]. They may have trouble sharing emotional difficulties, and some do not want to address distress and all [42]. In distress screening, we do not know how patients perceive the following conversation about psychosocial issues.

Effective patient-clinician communication encourages patients to openly express psychosocial needs, and to receive and understand information. The perspectives of patients and clinicians must be aligned in a patient-centered communication process designed to overcome barriers to effective communication [43]. Bultz, et al., [26] emphasize that interacting with the patient is the essential element of an effective screening procedure. Despite this, no screening tool offers detailed recommendations to guide physician interaction and communication with the patient. Discussing a patient's distress score on a screening tool opens an opportunity for physician and patient to effectively communicate about psychosocial issues and psychosocial health needs. Mitchell [44] reported that a screening tool like the Distress Thermometer positively influenced communications about psycho-social issues and distress; clinicians believed the screening program improved communication in more than 50% of assessments. Ours will be the first study to give attention to patient-physician communication stimulated by a distress screening instrument, and to ask how both patient and physician perceive the process.

Patient reasons for or against support service uptake

In their review, Dilworth and colleagues [27] describe the primary patient-reported reason for refusing support services as, "no subjective need for psychosocial services" (38.7% of pts). This broad reason could include, e.g., a preference for self-managing symptoms, not feeling distressed enough, the belief that help would be ineffective, and receiving sufficient support from family and friends. The second most important barrier in the Dilworth review is context-related. Patients reported they lacked information about the availability of psychological support services (19.0% of pts).

Studies that investigate the reasons patients choose or refuse psycho-oncological assistance rarely include qualitative aspects. A recent study [40] reported that, even in patients with high distress scores, a patient's preference for self-help and their belief that their distress is not severe enough are common barriers. Mosher [45] had similar results, and also identified inadequate knowledge of services as a patient-reported barrier. A qualitative study found that both a patient's desire for normalcy and their lack of information about the potential benefits of psycho-oncological treatment could lead patients to refuse psycho-oncological support. The subjective norms and information deficits of physicians also influenced the choice of patients to use psycho-oncological support services [46].

Limitations

The mono-center setting is both an asset and a liability. Conducted at one University Oncology Outpatient Clinic, our observational study is embedded in a clinic culture that takes a well-accepted interdisciplinary approach, including systematic integration of the psycho-oncological support service team. A study coordinator on the oncology team can closely monitor procedure. The single setting, however, may limit generalizability of our results.

Funding limits permits us only four months of follow-up, so we will not be able to draw long-term conclusions about uptake of psycho-oncological support at later stages of treatment, or in transition phases of illness.

The interviews we conduct may affect participant uptake of support services. This non-interventional observational study will interview participants twice, and ask them why they would or would not want to use psycho-oncological support services. Being asked these questions may motivate and interest participants in using support services. We cannot exclude this effect but, in the follow-up interview, we will ask the participant if this was one reason they used services.

Conclusions

To raise the quality of psychosocial cancer care, we need to move beyond simple diagnosis and consider the screening process as whole, from a health care delivery perspective. Better understanding the perspectives and potential difficulties in the communication process will help us craft recommendations to improve communication guidelines for distress screening. If we better understand determinants and barriers along the distress screening pathway, we may be able to increase access for underserved groups of distressed cancer patients. We hope to identify routine practices that can lower or eliminate barriers to adequate health care, and better meet patient needs, so we can deploy resources in psychosocial cancer care more efficiently and manage patients better.

Abbreviations

DT: Distress thermometer; ECOG Scale: Patient performance status according to Eastern Cooperative Oncology Group Scale; EKNZ: Ethikkommission Nordwest- und Zentralschweiz; ESSI: Social support inventory; FACT-G7: Health-related quality of life; FoP-Q-SF: Fear of progression questionnaire; HADS: Hospital anxiety and depression scale; PL: Problem list

Acknowledgements

This study is made possible by the financial funding of the Swiss Cancer League. We would like to thank Claudia Steiner for her help in the publication process. We also thank Kali Tal for her editorial contribution.

Funding

This study is financially supported by the Swiss Cancer League (grant number KLS 3186–02-2013). The funding body has no influence on the design of the study, the collection, analysis, and interpretation of data, or in writing the manuscript.

Availability of data and materials

Not applicable.

Authors' contributions

DZ, AK, CR, SR, MK are principal investigators and TT is the PhD Student of this study. DZ, AK and MK designed the study. CR and SR are collaborating oncologists contributing by critically revising the study concept. DZ and TT wrote on this manuscript led by DZ. All authors approved the final version of the manuscript.

Competing interests

The authors declare that they have no competing interests.

Consent for publication

Not applicable.

Ethics approval and consent to participate

This study will be conducted in accordance with the Declaration of Helsinki and Good Clinical Practice guidelines. The local Ethics Committee in Basel, Switzerland (EKNZ) approved the study (reference number EK 220/13). This local Ethic Committee is eligible to approve a study in the University Hospital of Basel.

Publisher's Note

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Received: 27 January 2017 Accepted: 16 May 2017
Published online: 30 May 2017

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Appendix B: Distress Thermometer

Universitätsspital Basel

Medizin
Onkologie

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Ihr ganzheitliches Wohlbefinden interessiert uns!

Sehr geehrte Damen und Herren

Körperliches und seelisches Wohlbefinden sind untrennbar miteinander verbunden. Die Diagnose einer Krankheit kann seelische Veränderungen bewirken – für direkt Betroffene und für ihre Angehörigen. Aus diesem Grund gehört die psychologische Fachperson zu unserem Behandlungsteam. Unsere Psychoonkologinnen, **Frau Franziska Durstewitz**, **Frau Astrid Grossert** und **Frau Diana Zwahlen**, betreuen und begleiten Sie und Ihre Angehörigen zusammen mit Ärzten und Pflegenden, wenn Sie dies wünschen. Diese Leistung wird von der Krankenkasse übernommen.

Für eine erste Einschätzung Ihrer momentanen Belastungssituation, möchten wir Sie bitten, auf der **Rückseite** dieses Blattes den so genannten „Belastungsthermometer" auszufüllen.

Bitte geben Sie den Fragebogen anschliessend Ihrem **betreuenden Arzt oder Ihrer Ärztin** bei der Konsultation ab. Er oder sie wird Ihre Angaben mit Ihnen besprechen.

Ihr Team der Onkologie Basel

Sprechstunden nach Vereinbarung

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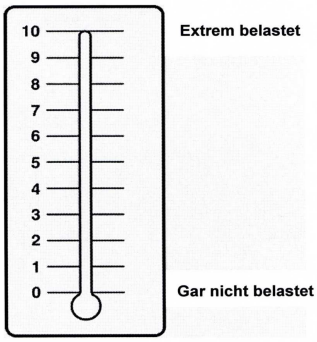
Weitere Informationen unter:
http://www.unispital-basel.ch/das-universitaetsspital/bereiche/medizin/kliniken-institute-abteilungen/onkologie/

Etikette	Datum:	Visum Arzt:

ERSTENS: Bitte kreisen Sie am Thermometer rechts die Zahl ein (0-10), die am besten beschreibt, wie belastet Sie sich in der letzten Woche einschliesslich heute gefühlt haben.



ZWEITENS: Bitte geben Sie an, ob Sie in einem der nachfolgenden Bereiche in der letzten Woche einschliesslich heute Probleme hatten. Kreuzen Sie für jeden Bereich **JA** oder **NEIN** an.

JA	NEIN		JA	NEIN	
		Praktische Probleme			**Körperliche Probleme**
○	○	Wohnsituation	○	○	Schmerzen
○	○	Versicherung	○	○	Übelkeit
○	○	Arbeit/Schule	○	○	Erschöpfung
○	○	Beförderung (Transport)	○	○	Schlaf
○	○	Kinderbetreuung	○	○	Bewegung/ Mobilität
			○	○	Waschen/ Ankleiden
		Familiäre Probleme	○	○	Äusseres Erscheinungsbild
○	○	Im Umgang mit dem Partner	○	○	Atmung
○	○	Im Umgang mit den Kindern	○	○	Entzündungen im Mundbereich
			○	○	Essen/ Ernährung
		Emotionale Probleme	○	○	Verdauungsstörungen
○	○	Sorgen	○	○	Verstopfung
○	○	Ängste	○	○	Durchfall
○	○	Traurigkeit	○	○	Veränderungen beim Wasser lassen
○	○	Depression	○	○	Fieber
○	○	Nervosität	○	○	Trockene/ juckende Haut
○	○	Verlust des Interesses an alltäglichen Aktivitäten	○	○	Trockene/verstopfte Nase
			○	○	Kribbeln in Händen/ Füssen
			○	○	Angeschwollen/ aufgedunsen fühlen
		Spirituelle/religiöse Belange	○	○	Gedächtnis/ Konzentration
○	○	In Bezug auf Gott	○	○	Sexuelle Probleme
○	○	Verlust des Glaubens			

Sonstige Probleme:

Procedere (Arzt):

Verlauf (PsyOnk):